The Impact of Moving Home to the Identity of People with Learning Disabilities

Margarita Karavella

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City University, London

Department of Psychology

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Declaration

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Abstract

The goal of the following portfolio is to explore the experience of people with learning disabilities when moving from the family home to a care home, as well as, to understand the impact that this change has on the identity of this population. This is the focus of the research presented. Furthermore, this portfolio includes a case study and a critical literature review. The case study presents counselling work carried out with a client with learning disabilities deciding to move from her family home. The critical literature review aims to explore and present approaches and tools that are employed in bereavement counselling for people with learning disabilities and to critically evaluate current literature on approaches used in bereavement counselling for this population.

Symbols and Abbreviations Key

CBT   Cognitive Behavioural Therapy

IPA   Interpretative Phenomenological Analysis

LD   Learning Disabilities

Part A: Preface

1. Preface

The present portfolio covers a range of my experiences and interests that have been developed while conducting my DPsych level research and therapeutic practice. My interest in the area of learning disability started before the beginning of my postgraduate training. This portfolio reflects on my own development as a researcher and practitioner in the field of identity and learning disability, and presents what I consider to be essential when working with people with a learning disability. This research together with my counselling practice have given me the opportunity to evaluate and expand current counselling approaches towards people with a learning disability, as well as, to shed some light on the process of residential care transfer and its impact on the identity of this population.

2. A Definition of Learning Disability

Before I continue any further with this portfolio, it would be beneficial to provide a learning disabilities definition. According to *Valuing People*, the 2001 White Paper on the health and social care of people with learning disabilities, learning disability includes the presence of:

> *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development (Department of Health, 2001).*

This definition is broadly consistent with the one used in the World Health Organization's International Classification of Disease (ICD-10), although the former does use the outdated and (to many) offensive term 'mental retardation' (WHO, 1992; WHO, 1996). The term learning disability was introduced in the UK to replace the term 'mental handicap'.

However, many people with learning disabilities prefer to use the term 'learning difficulty'. The two terms are interchangeable when used in the context of health and social care for adults. However, in the UK educational services, the term 'learning difficulty' also includes people who have 'specific learning difficulties' (e.g., dyslexia), but who do not have a significant general impairment in intelligence. However, the Special Educational Needs (SEN) codes of 'moderate learning difficulty', 'severe learning difficulty' and 'profound multiple learning difficulty', all refer to a generalised learning difficulty of varying severity (Department for Children Schools and Families, 2009). Taken together they can be considered to be interchangeable with the adult health and social care term 'learning disability'. However, people with specific learning difficulties such as dyslexia do not have 'learning disabilities' The UK is the *only* country that uses the term 'learning disability' in this way. An increasing number of international organisations and countries (e.g., USA, Canada, Australia) use the term 'intellectual disability'. The term 'intellectual disability' should be considered interchangeable with the UK term 'learning disability' (Emerson & Heslop, 2010).

3. What this Portfolio is about: Moving Home and People with Learning Disabilities
A significant proportion of the population of people with learning disabilities live with members of their family (Walker & Walker,1998; Ward, 1998; Department of Health, 2001; Blackman, 2003). If a person with a learning disability lives in the family home, when a parent dies, this can lead to a sudden move into residential care. There might be also the possibility that the family can no longer provide care for the person with learning disabilities at home in the way that they previously did (Worden, 1983). The result would be again a residential transition for the person with learning disabilities. The move in those instances is likely to become a crisis placement and there might be no chance for any preparation for the person with learning disabilities (Blackman, 2003). This might mean that people with learning disabilities may have to cope with multiple losses: that is, not only the loss of a loved one, but also of their home, routine, the familiar environment and their contact with family and friends. Moving from the family home is a significant transition in the life of a person with learning disabilities. Being part in the decision making about the move, as well as, being prepared for it, are two important parameters

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that may assist the person with learning disabilities to have a better adjustment in the new home. However, this process of moving home is not merely a series of events; rather it is a fluid process that has a direct impact on the concept of the self of the person with learning disabilities. This DPsych portfolio seeks to explore the experience of moving home for the learning disability population and its possible links to their identity (a re-shaping of their identity).

Counselling psychologists, who work with clients with learning disabilities, should seek to extend their awareness of how this client group experiences residential transition and how this affects their identity. As counselling psychologists, we can understand the process of transition and change in everyday life. Professionally we are also aware of our own transitions and of our selves evolving along with our life changes.

Many people with learning disabilities may not be prepared for changes to take place in their lives, especially such as moving home. Although their families and keyworkers may be involved during the moving process and give their support, support is also needed in the care home environment. Sometimes care home staff is not adequately trained to manage the emotional needs of the person with learning disabilities, as well as, to monitor any changes in their character, mood and behaviour. Much research has been done to indicate tools and interventions used in relation to bereavement and loss as experienced by the learning disability population. These assessment tools and interventions have been further explored in the critical literature review section of this DPsych portfolio.

The goal of the following portfolio is to explore the experience of people with learning disabilities when moving from the family home to a care home, as well as, to understand the impact that this change has on the identity of this population. My own experience of working with clients with learning disabilities has guided the research, case study and literature. By elaborating on the identity of this population, the portfolio hopes to present a different kind of home transition process. By exploring the place identity alongside the residential transition, the portfolio seeks to give people with learning disabilities a voice,

so as to shed some light into their own meaning and sense of this experience, so as to improve the support services offered to this population.

There has been an ongoing research carried out in both fields of residential transition and identity, and identity and learning disability. However, there is little research on the impact of moving home in relation to the identity of people with learning disabilities. The following portfolio will seek to elaborate on this topic.

Up to an extent the transition does not only involve the move to the new home, but also the 'move' to a new self. The transition as a phenomenon can affect other aspects of participants' lives as well.

The portfolio includes a case study of counselling work carried out with a client with learning disabilities deciding to move from her family home. The main components of the portofolio derive from my professional experience of working with people with learning disabilities, where I use the psychodynamic approach, along with bereavement counselling and therapy work focusing on loss and transition. The portofolio also draws from my experience of doing therapy work with carers, the knowledge I gained during the learning disability research I conducted at a Master's level. Lastly, it is broadly informed by my ongoing interest in the use of counselling psychology in the learning disability field. Furthermore, the portofolio addresses other studies on residential transition, aiming to elaborate on the experience of moving home and its impact on identity, as well as, the therapeutic interventions that can be used in this area. My professional work on residential transition provided me with interesting observations as to how people with learning disabilities react when moving to a new environment to settle down and cope with changes in their life. The interesting aspect of moving home is not the actual process of moving, but its effect. In other words, how participants' previous identity, choice and degree of independence evolve to a new self. I believe the portfolio offers a rounded study of the experience of moving home for people with learning disabilities and its influence on their self concept and how practitioners can work clinically with these emerging issues. The portfolio offers a balance of perspectives from the area of identity and residential relocation, which will contribute to a gap in the current research and literature.

Several different sources were used directly and indirectly for the constitution of this portfolio. Professional work conducted at a disability non-profitable organization and in a bereavement counseling service, both in London, and in a general counselling service in the Berkshire area, provided me with the experience of working with people with learning disabilities that have experienced life transitions, loss and bereavement and also with some contacts for participant interviews. Several clients from the disability service showed identity issues because of sudden life changes. These clients had often experienced loss of a loved one or change in their immediate environment, ie. change of their keyworker, moving home etc. The majority of clients struggled with their disability in relation to their transition. The counseling service based in Berkshire provided a learning disability project for clients experiencing trauma and bereavement living in the community. In this service the main cases involved loss and bereavement.

The services enhanced my knowledge of the psychodynamic approach, and provided me with clients for the portfolio case study and useful liaisons with the learning disability population for the interviews. Another professional source for the portfolio was the Child and Family Consultation Service as part of the South Essex Partnership NHS Foundation University Trust in South Essex. My work as a Chartered Counselling Psychologist at the service has informed the research and professional work in the area of residential transition of children with learning disabilities in foster care, in the area of therapeutic interventions regarding children and adolescents with learning disabilities, and in the area of supporting carers and foster carers. Assessments and therapeutic work conducted at CFCS provided me with a better understanding of residential transition and its impact on clients' lives.

Other primary and secondary sources used throughout the portfolio include journals, university and professional libraries, websites, workshops, presentations, lectures and textbooks. Fields and topics researched included health, counselling and clinical psychology, social work, sociology, research methods, qualitative research, interpretative phenomenological analysis, phenomenology, hermeneutics, identity, learning disability,

stigma, place identity, residential relocation, residential placements, deinstitutionalization, governmental policies, loss and bereavement, bereavement counselling, and psychodynamic psychotherapy. Occasionally, secondary sources were the only sources available for some parts of the portfolio. This was due to difficulties in locating sources using online journals.

The majority of sources came from searching on the topic of identity and learning disability and transition, and their corresponding fields. The overlapping of these four main areas and their interrelation also indicate the objectives of this DPsych portfolio.

4. DPsych Portfolio Overview

4.1. Section B: Research

Title: The impact of changing home on the identity of people with learning disabilities

4.1.1. Aims & Objectives
This research aims to investigate, using an Interview Schedule, the experience of moving home of people with learning disabilities and its impact on their identity.
That is, how the change of the environment from the family home to a care home can influence the identity of a person with learning disabilities.

More specifically, the objectives of this research could be summarised in the following way:
- To identify what is understood by change of context e.g. home
- To explore feelings and emotions that are often associated with this change
- To explore the experience of change from family home to a care home
- To discuss change of home from a personal perspective
- To identify changes in self-concept/ personality, if any, after the change of home
- To discuss how one perceives his/her social identity after this change

- To identify coping mechanisms or personal support mechanisms that might have been developed with this experience.

4.2. Section C Professional Practice

Title: Working with transition and change: Psychodynamic Counselling with a Client with Learning Disabilities

4.2.1. Aims & Objectives

The presentation of the client case of Nadya describes an individual with learning disabilities and with issues around her relationship with her parents, her disability and her degree of dependence from her family. This case study explores Nadya's problem as it is presented and assessed by herself, and discusses her decision to move out of the family home – a decision that came up during the course of her psychodynamic therapy. The study also shows the process of Nadya's transition from her family home to the care home and how transition and change were addressed and managed in the course of therapy.

4.3. Section D Critical Literature Review

Title: Bereavement Counselling for People with Learning Disabilities: A Critical Literature Review

4.3.1. Aims & Objectives

This critical literature review aims to explore and present approaches and tools that are employed in bereavement counselling for people with learning disabilities. The review critically evaluates current literature on approaches used in bereavement counselling for this population and their effectiveness. Apart from therapeutic tools and approaches, this section presents findings regarding the experience of loss of people with learning disabilities, as well as, the considerations and accounts of counselling psychologists with the aim to offer a better insight into the needs of this population. The review focuses also on gaps in research and suggestions regarding methods and tools that could improve clinical practice.

This portfolio offers an in-depth understanding of the process of residential transition and its impact on the identity of people with learning disabilities. It illustrates how practitioners can understand the experience, the complexity and the difficulty people with learning disabilities face when moving home and offers an insight into ways to support them during their transition and adjustment in their (new) home and their (new) identity.

5. Final Note

A great deal of time and energy was invested into this DPsych portfolio, not only for the purpose of submission, but also for highlighting some important areas within the area of working therapeutically with people with learning disabilities. The portfolio's research component presents a study that draws on qualitative research methodology (more specifically interpretative phenomenological analysis). This study aims to reflect the overall portfolio's aim, which is to give value to the voice of people with learning disabilities and to their experiences. As an individual and as a practitioner I value deeply every person's right to be heard and listened without prejudice. I believe that everyone needs to be respected and to be treated equally. For me this research does not only reflect my motivation to work with this population, but also reflects my philosophy in life. The strengths of this DPsych research lie on its rigorous research procedure and on some very interesting conclusions. The case study presented here, demonstrates the significance of the psychodynamic approach in counselling when working with transition and change of the home environment. Finally, the critical literature review evaluates relevant literature and gives an insight into the therapeutic tools and approaches that are used when working with people with learning disabilities on issues such as loss and bereavement. It further suggests a battery of clinical interventions for practitioner psychologists in order to enhance their clinical practice with this population.

I hope the portofolio has accomplished its task, which is twofold: to stress the significance of counselling psychology in the field of residential transition and identity for people with learning disabilities, and to point out the importance of appropriate interventions.

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Part B: Research

Title: The impact of moving home to the identity of people with learning disabilities

Abstract

The way in which people with learning disabilities experience moving out of the family home has not been extensively researched. This is surprising given the fact that service users, families and staff frequently ask for support during the time of residential transition. The aim of this research project was to explore the experience of moving home for adults with learning disabilities and how it impacts on their identity. Although a variety of research studies have been conducted in the area of transition for people with learning disabilities, many have not directly involved this client group, or have not focused on the transition's impact on their identity, thus opening a dialogue with relevant literature on identity. Consequently, there is a gap in our understanding regarding the experience of transition from the family home to the care home for this client group and the range of issues that emerge for their self concept. Fourteen semi-structured interviews on the experience of residential transition were conducted with adults with learning disabilities, who in the past had moved out of their family home to a care home. The interviews were transcribed and analyzed using interpretative phenomenological analysis (IPA) (Smith, 2004). From the analysis of participants' accounts five main superordinate themes were identified. The first, 'who I am', described the participants' identity. The second, 'the move', described the participants' moving experience. The third, 'the new home', described the participants' views about their home. The fourth, 'things changed after I moved', described change following the participants' move to the care home. Finally, 'my self after the move', described the participants' identity after moving to the care home. The findings of this study can also be used to inform the clinical practice of professionals, who work with the learning disability population. Ideas for further research, as well as, the implications of the role of the Counselling Psychologist were also explored.

The Impact of Moving Home to the Identity of People with Learning Disabilities

1. Chapter 1: Introduction to the Area of Research

The Ancient Greek philosopher Heraclitus said that "everything flows"[1](Plato, 401d, 5), that "All things move and nothing remains still"[2] and that "Everything changes and nothing remains still .... and ... you cannot step twice into the same stream"[3] (Plato, 402,a, 8). Heraclitus spoke about change and how everything in life changes and evolves and, thus, cannot return to its previous state like the waters of a river. Transition and change are part of life itself. Almost every day people come across changes in their lives, either personal or professional, in their relationships and in their routines. Change is inevitable and people need to embrace it and adjust to new situations so that they can move on. As with the mainstream population, change affects frequently the lives of people with learning disabilities, often bringing them several difficulties.

As a trainee counselling psychologist, I worked frequently with the meaning of change in clients' lives. Very often, people came to therapy in order to change. Change was,thus a goal, not only an everyday phenomenon. Apart from my clinical work, I focused on change in the context of my MSc research, where I investigated the experience of bereavement for adults with learning disabilities. Before and during my training as a counselling psychologist, I worked with people with learning disabilities and I was interested in understanding their needs.

People with learning disabilities often face simultaneous losses (Humlin, 2003). This is because the death of their loved one is not the only loss they may experience. The death may bring many different changes. Change of home, changes of people around them and changes in their everyday routine are additional losses connected to their bereavement. Loss of mobility, loss of functioning and companionship are areas that have to be identified so that the individual can adjust to an environment (James, 1995).

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[1] In greek Τα Πάντα ῥεῖ =*ta panta rhei* (Plato, 401d, 5)

[2] In greek τὰ ὄντα ἰέναι τε πάντα καὶ μένειν οὐδέν''=Ta onta ienai te panta kai menein ouden (Plato, 402a, 8)

[3] In greek *πάντα χωρεῖ καὶ οὐδὲν μένει*'' καὶ "*δὶς ἐς τὸν αὐτὸν ποταμὸν οὐκ ἂν ἐμβαίης"*= Panta chōrei kai ouden menei ... kai ... dis es ton auton potamon ouk an embaies (Plato, 402a, 8)

A prominent theme that came out from my data analysis as a postgraduate student was the issue of change after the death of their loved ones. Participants talked extensively about changes in their personality, in their relationships and in their everyday living and functioning. Several spoke about changing homes after their bereavement. Naturally, the concept of change brought in my mind thoughts about how a changing context can shape the identity of an individual with learning disabilities and how the self-concept of this client group is moulded after such an event.

As the changing of home was a common experience among my participants, I got inspired and intrigued by this experience and wanted to pursue a further understanding of how this client group experiences this transition. This raised a variety of questions and prepared the ground for further research. The main research question that I was eager to investigate was: what is the impact of change (e.g. change of home) on the identity of people with learning disabilities? More specifically, how can change from a family home to a care home influence the identity of a person with learning disabilities?

2. Overview of the Research

People with learning disabilities constitute an underprivileged group, which has faced many prejudices over the years. Even in times when there is a governmental supportive strategy for people with learning disabilities, the general view that society holds towards people with such disabilities continues to be problematic. According to Owen, Hubert and Hollins (2007), "people with severe intellectual disabilities are seen as being too different, too disabled and too challenging to lead lives like 'us'. They are not thought of as people who have pasts, have emotions, who experience feelings of loss, who grieve for old friends, who feel anxious about change, who have sexual needs or who suffer from loneliness. Furthermore, it is still often believed that the reason for these perceived differences lies in their disability, rather than in what they are taught, the opportunities they are given, how they are supported and the expectations of those around them" (Owen, Hubert and Hollins, 2007, p,6). Their learning disability prevails and comes first, surpassing their other qualities. Therefore, it is of paramount importance to give a true

depiction of people with learning disabilities, bring their views forward to society and promote their rights and wishes by giving them a voice and a face instead of a label. This was also my aim in this research project: to let the voice of people with a learning disability be heard and take into serious consideration their views and feelings about changing home.

The section of literature review will describe the definition criteria of learning disabilities, and discuss the transitions these people frequently face throughout their lives. In particular, it will examine the experience of moving home for people with learning disabilities, usually, a moving out from the family home to a care home, and discuss such an experience within the context of identity, home and residential relocation. The literature in this chapter will be evaluated further in the Discussion Section, where I will analyse and discuss critically the findings that have emerged from my study in relation to pre-existing relevant research and wider literature.

In order to complete this literature review, a search of various databases was conducted, such as PsycINFO, Ovid online, PsycArticles, ScienceDirect, Electronic Journals Library, BPS Research Digest etc. Search terms included combinations of words including 'learning disabilities' (and synonyms), 'home', 'moving out', '(residential) transition', 'residential relocation' and 'identity'. Further information was accessed from the Department of Health website and various learning disability organisations and charities. Learning disabilities

In this study I have chosen to use the phrase 'people with learning disabilities' to describe the population that I am researching, as this is the term that is most widely used in the UK. There are various terms used in other disciplines and in other countries. For instance, academics often use the term 'intellectual disability', while in the US terms such as 'mental retardation', 'intellectual impairment' and 'developmental disability' are widely used. Some service user led organisations in the UK such as People First prefer to use the term 'learning difficulties' but they also acknowledge that this can lead to confusion with specific learning problems such as dyslexia (Jones, 2010). They argue that there is no

clear-cut decision as to what the most appropriate term should be, but that any label should be used in a clear, inclusive and positive way (BILD, 2006). The primary aim of this research is to give voice to people with learning disabilities and I hope that they have been handled with care and discussed in a respectful way throughout the research process.

3. Learning Disability Definitions

There are various definitions for learning disability since it is a term whose meaning has often been debated. In the past, people lacked awareness of the issue of learning disability and confused it with mental illness (Chesner, 1995). This attitude may have been responsible for the marginalization of this group and for its place in society (i.e. where people with learning disabilities should live).

The term learning disability was linked with the term mental handicap, which refers to the emotional and social consequences of one's mental impairment (Sinason, 1992). However, a more thorough definition was provided by O'Hara and Sperlinger (1997) that connected learning disability with "mental retardation" and defined it as a significant below average intellectual functioning that appeared before the age of 18 and caused limitations in two or more of the following areas: communication, social skills, self-care, living at home, health and safety, hobbies and work, academic skills and use of community resources. Emerson (1995) completed this definition by adding that a person with severe learning disability manifests: an additional physical or sensory handicap, impairment in the central nervous system, exhibited signs of major disabilities in acquiring adaptive behaviours from an early age that imply their need of more support in order to function, and a low score (below 50) on standardized IQ tests. Current literature reported five learning disability categories that reflect the various degrees of learning disability. These are borderline, mild, moderate, severe and profound. The causes of learning disability are various including genetic disorders, cranial impairment, chromosomal anomalies, congenital, psychosocial and environmental factors (Thomas and Woods, 2003).

4. Diagnostic Features of Learning Disabilities

4.1. DSM-IV Criteria for learning disabilities

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) Criteria for mental retardation are the following:

A. Significantly subaverage intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgement of significantly subaverage intellectual functioning)

B. Concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.

C. The onset is before the age of 18.

Based on the degree of severity that reflects the level of intellectual impairment, the following categories are formed:

- Mild Mental Retardation: IQ level 50-55 to approximately 70

- Moderate Mental Retardation: IQ level 35-40 to 50-55

- Severe Mental Retardation: IQ level 20-25 to 35-40

- Profound Mental Retardation: IQ level below 20 or 25

- Mental Retardation, Severity Unspecified: when there is strong presumption of Mental Retardation but the person's intelligence is untestable by standard tests. (2000, p.49)

4.2. Population Statistics

The 2001 Department of Health White Paper, 'Valuing People', estimated that there are approximately 120,000 people with severe and profound learning disabilities, and 1.2 million people with mild/moderate learning disabilities in the UK (DoH, 2001, p15.) However, estimates tend to vary according to the definition of learning disabilities used

(Allgar et al, 2008; Whitaker & Read 2006). For instance, Emerson & Hatton (2008, CEDR) estimated that there are 985,000 people in England, who have a learning disability, of whom 828,000 are adults. However, only 177,000 were users of learning disability services (Jones, 2010).

4.3. Causes of Learning Disabilities

The causes of learning disabilities vary. The American Psychiatric Association (DSM-IV-TR, 2000) states that the etiological factors of learning disability may be primarily biological, psychosocial or a combination of both. Major predisposing factors include heredity, early alterations of embryonic development, environmental influences, mental disorders, pregnancy and perinatal problems and general medical conditions acquired in infancy or childhood. Other academic sources acknowledge prenatal factors (e.g. chromosomal disorders, genetic disorders, or maternal factors), perinatal factors (e.g. prematurity, asphyxia, intra-uterine infections, haemorrhaging, or umbilical cord accidents) and postnatal factors (e.g. infections, degenerative disorders, epilepsy and head injuries) (Sperlinger, 1997). High levels of social and material deprivation combined with poor access to maternal health care can also increase the risk of having a child with a learning disability (Emerson, Hatton, Bromley & Caine, 1998).

4.4. Comorbidity

People with learning disabilities often encounter additional biological difficulties. These include physical disabilities, sensory impairments, autistic spectrum disorders, epilepsy and early onset dementia. They are also at an increased risk of developing health conditions (Kappell et al, 1998). The most common associated mental disorders in the learning disability population are attention-deficit hyperactivity disorder, mood disorders, pervasive developmental disorders, stereotypic movement disorder and mental disorders due to a general medical condition (DSM-IV-TR, 2000).

5. Identity

Before continuing with relevant literature on residential transition, learning disability and identity, it is pivotal to further explore definitions on the concept of identity.

Self, ego, I and me are all terms that have been used interchangeably for identity (Kroger, 2007). The concept of identity is very difficult to define (Beart, Hardy & Buchan, 2005). Many definitions have been used over the years for it. For instance, Sarup viewed identity as 'the story we tell of ourselves and which is also the story others tell of us'(Sarup, 1994, p, 91). Breakwell (1983) supported that the terms identity, self, character and personality are all used to express that uniqueness which differentiates one person from the next. On the other hand, Deaux (1992) defines identity by contrasting it with the concept of self, linking the former to social roles and the latter to personal internal and external characteristics. Hurrelmann (1988) emphasizes the continuity of self-experience in identity defined as having a continued sense of who we are across lifetime social roles and biological changes.

5.1. The Self Concept

Cooley (1902) proposed the concept of a 'looking-glass self' to describe the development of the self-concept. He claimed that people see themselves as others see them because they learn about themselves from others. Others effectively act as mirrors in which a person sees himself or herself. His description entails an infinite regress of mirror reflecting mirror: each acts as a mirror for others and responds to the mirrors that others are for them. Cooley is actually describing the growth of the self-concept through a refined metaphor.

Mead (1934) made the distinction between 'I' and 'Me' and tried to describe the processes engaged in the evolution of this distinction. According to Mead, the self develops as a result of its relations to the 'generalized other'. The reactions and expectations of those that are important to us are the template of our behaviour. The 'generalized other' is composed of one's apprehension of those around him/her. Therefore, everyone learns to interpret the world as others do in order to act as expected.

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Furthermore, Mead differentiates between the 'I' and the 'me' by giving them different contexts in which to operate. 'Me' focuses on interchanges involving group membership, status, roles and other people. 'I' involves the person asserting himself/herself against the situation, underlying his or her unique abilities (Mead, 1934).

5.2. Personal and Social Identity

During the past years, there have been many debates around the concept of identity and the different aspects of self. One of the debates focused on the distinction between personal and social identity. According to Breakwell (1983), social identity is that part of the self concept emerging from the individual's group memberships, interpersonal relationships and social position and status. Personal identity is that part of the self-concept which is free of role or relationship determinants. There is evidence to suggest that people do experience both aspects of identity (Turner, 1976).

Tajfel (1978) has aimed to describe this distinction by envisaging a continuum where personal identity lies on one end and social identity on the other end. On the other hand, Brewer (1991) formulated his ideas using personal identity as the centre of the self and other group identifications surrounding it with greater inclusiveness. Reflecting upon the existing literature around this distinction, identity seems to encompass both aspects of the personal and the social self. Sometimes, it is very difficult to distinguish one from the other since both of these aspects are so interwoven.

Other writers have emphasized the importance of social identity (Craib, 1998; Burkitt, 1991; Mead, 1934). People can actively accommodate and assimilate aspects of self as they are offered by the social world (Gergen, 1977) and consequently, their personal identity can be the product of social identities (Breakwell, 1983). This usually occurs because people define themselves according to how they perceive others responding to them through verbal and gestural communication. Individuals not only become aware of the impact they have on others, but they also use that awareness to determine future communications of the self. Individuals carry within themselves a whole series of

different relationships to different people and, thus, the unity of one's experience of self is merely a reflection of the unity in one's social experience (Kroger, 2007). Within this framework, Breakwell (1983) has argued that social identities provide templates for self-conception, that is, a structure and an evaluation of that structure. To this extent, personal identity is the product of social identities. It is therefore difficult to view personal identity without one's social history and context, since people experience both a personal and a social identity. The same processes apply to people with learning disabilities according to relevant literature. For instance, Dudley-Marling (2004) in his study on the social construction of learning disabilities has demonstrated with several examples how the learning disability identity is constructed in the context of social relations.

Breakwell (1983) noted that the distinction between social and personal identity is more likely to be felt when they are in conflict with each other. When an individual finds that his/her social role requires one course of action and his/her personal feelings demand something else, the individual becomes aware of both his personal and social identity. The interesting thing is that this distinction between personal and social identity may remain unobserved if there is no conflict.

5.3. Roles and Multiple Identities

Goffman (1959, 1967) used the metaphor of theatre to analyse social life as dramaturgy and the self as various role-playing and dramatic performances that take place on the social stage. The quality of the performance is essential to our sense of self, since these performances deliver impressions to others and information is exchanged to confirm identity. The roles are not freely chosen but socially scripted in congruence with the statuses, roles and relationships as they are accorded by the social order.

Breakwell (1983) similarly has argued for the multiplicity of social roles stating that one can occupy several social roles simultaneously. She believed that these roles contribute to make one's social identity and can be either private or public.

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James and Mead also proposed the multiplicity of identity early in the 20th century (Breakwell, 1992). Mead said "we divide ourselves up in all sorts of different selves with reference to our acquaintances' and 'a multiple personality is in a sense normal" (Mead, 1934/1962, 142). In the same spirit, a number of researchers have shown that multiplicity is not only conceptually reasonable but also psychologically desirable (Breakwell, 1992). Some researchers suggested that multiple roles diffuse the stress experienced in any single role and that multiple roles reveal greater self-complexity (Thoits, 1983; Linville, 1987; Kelly, 1955).

5.4. Group Membership and Social Identity Theory

There seems to be much discussion around the meaning of group membership and its emotional significance to the individual (Breakwell, 1983). The group is defined by Tajfel (1978) as a cognitive entity that is meaningful to the individual at one point in time, with the outcome that the salience of different group memberships will vary over time and context (Finlay & Lyons, 1998). It is important to note that an individual's self definition will be influenced by their group memberships to varying levels (Breakwell, 1986). Newman and Newman (2001) emphasized the critical role that group identifications play in the process of individual identity development, especially in early adolescence. The capacity to invest in and to commit oneself to various social networks provides the foundations and the necessary support for later individual identity exploration and commitment (Kroger, 2007).

Social Identity Theory is concerned with group situations and starts from the assumption that social identity is derived primarily from group memberships. It further proposes that people strive to achieve or maintain a positive social identity and that this positive identity derives largely from favourable comparisons that can be made between the ingroup and relevant outgroups. In the event of an 'unsatisfactory' identity, people may seek to leave their group or find ways of achieving more positive distinctiveness in it (Brown, 2000).

The key proposal of social identity theory, however, is that it is the extent to which people identify with a particular social group that determines their inclination to behave in terms of their group membership. In this sense, social identification is primarily used to refer to a feeling of affective commitment to the group, rather than the possibility to distinguish between members of different social categories (Ellemers, Kortekaas & Ouwerkrk, 1999).

5.5. *Idioprosopia*

A novel concept that resembles identity but goes even further in meaning is idioprosopia, its roots lying in group analytic literature. This term (idioprosopia) derives from the Greek words (idios) and (prosopon). Idios means special, particular, private. Prosopon comes from the synthetic words 'pros' that means towards and 'Ôops' that mainly means eye and look. So, prosopon (neither prosopeion, mask or persona, nor person) is the human hypostasis on the way of being, who sees and expresses himself, especially with the Ôtoward, the eyes' part of head, that is the face. Therefore, idioprosopia is the way that a particular prosopon positions himself in relation to a position, attitude and behaviour of anybody else and a group as a whole. It is neither one's possible or predetermined attitude in relation to his/her environment, nor is it his peculiar shape, the mental characteristics, the elements of his mind as human being; all of them are stable, known or expected. Prosopon does not give priority to his nature but to the expression of his nature. Idioprosopia includes the possibilities of being:

- free and independent, unified and unique
- unexpected but transitional, non-repetitive but concrete

It is one's way of being without predetermined attitudes in relation to his/her surroundings. (Kritikou, 2000; Menoutis, 1997, 2000, Menoutis & Kritikou,1996).

5.6. Threatened Identities

According to Breakwell (1983), any experience can potentially constitute a threat to an individual's identity. Any thought, feeling, action or experience, which challenges one's personal or social identity is a threat. The challenge can be at one or both levels:

- it may involve the content of the personal or social identity or
- it may involve its evaluation.

In terms of the content, identity encompasses labels a person would use to describe oneself. A threat, which could attack the content of an identity. might enquire whether these labels were apt. In terms of the evaluation, this threat questions the value of one's identity. The potency of these two types of threat seems to be detrimental to the person's self-esteem. The threats to self-esteem operate on three levels: attaching the individual, attacking the individual's group memberships and attacking the individual's group. Sources of threat are the individual himself, other people and the material world (Breakwell, 1983).

5.7. Identity and Stigma

The term stigma refers to an attribute that is deeply discrediting. A stigma is a special kind of relationship between attribute and stereotype (Goffman, 1963). There are three different types of stigma:

- the physical deformities of the body
- the blemishes of individual character (ie. weak will, domineering etc)
- the tribal stigma of race, nation and religion.

The stigmatised individual tends to hold the same beliefs about identity as others do. The individual's deepest feelings about what he/she is may be his/her sense of being a 'normal person', a human being like anyone else (Goffman, 1963).

5.8. Identity, Self-Concept and Learning Disability

The term 'self-concept' accounts for a significant portion of achievement of measured intelligence, socio-economic status, educational aspirations, and the expectations of

family, friends and teachers (Brookover *et al.*1965; Jones, 1985; Fitts, 1972). In general, research on the self-concept of people with learning disabilities is very limited and has been mostly related to school achievement and educational setting. Results show that children with learning disabilities have a lower self-concept than any other group (Jones, 1985; Fitts, 1996). The common assumption has been that identifying children as exceptional and isolating them from the larger school population has resulted in a diminution of self-concept, as a reaction to the stigmatizing effect of handicapped labels (Coleman, 1983). Researchers in the area have speculated that children's self-perceptions may best be best understood in accordance with the theory of social comparison. Social comparison theory (Festinger, 1954) suggests that, in the absence of objective standards of comparison, people will employ others in their environment as the basis for forming estimates of self-worth. Comparisons between integrated and non-integrated educational settings have shown contradictory results. In their study, Madden & Slavin (1983) have found that one of the results of integration was the enhancement of self-concept.

However, other studies have shown that children in integrated settings experience humiliation, social denial and failure, all of which serve to reduce one's self-concept. This is due to the fact that self-concept is built through interaction with one's closest environment. In his study on the influence of special education on children's self-concept, Coleman (1983) has found that the special education classroom created a more homogeneous social comparison group and that their placement in segregated classes actually increased self-concept rather than lowered it. In his study on young adults attending vocational transition programmes, Price (1991) showed average normative scores on self-concept measures. Self-concept is a social phenomenon arising and developing within a social context, and multiple comparison groups enable people with disabilities to use these groups selectively. As a result, they are able to maintain some control over the self-assessment process.

Most research studies have compared the self-perceptions of people with disabilities with the perceptions significant others, such as parents, teachers and social workers have of them. (Reiter & Bendov, 1996). Apparently, individuals with disabilities tend to rate

themselves more positively than others do (Adelman *et al.* 1979; Brayen, 1982; Alvarez & Adelman, 1986; Klein *et al.,* 1988; Raviv & Stone, 1991). Several explanations have been offered for this phenomenon. Parents, teachers and social workers may not be communicating clearly with the people with disabilities as the result of barriers caused by the disability itself. Individuals with disabilities may be socially misunderstood insofar as non-disabled people tend to perceive the disability rather than the whole person behind it (Reiter & Bendov, 1996). Several studies on the personal self-concept of individuals with disabilities have shown that, despite the expectation of a negative self-concept, this has not been unanimously confirmed by research results (Deshler *et al.*, 1978; Cruickshank *et al.*, 1980; Parish *et al.*, 1980; Coleman, 1983; Reiter & Bendov, 1996).

Ever since the beginning of the movement towards community integration, with the emphasis on the individual's perceived quality of life, the focus has been on social environment variables promoting or hindering satisfaction and a sense of well- being (Schalock, 1996). In the past few years, there has been an increasing tendency of encouraging people with disabilities to join the social activities, which community centres offer to the general population. Duvdevany (2002) examined the effect of the inclusion of individuals with learning disabilities in the social activities in community centres in Israel, and more particularly, its effect on their perceived self-concept and their adaptive behaviour. A comparison was done with a similar group belonging to segregated social clubs. Differences were found in two subscales of self-concept. Firstly, the physical self-concept of individuals with learning disabilities who participated in integrated programmes was found to be higher than that of their counterparts, who participated in segregated programmes. Secondly, satisfaction with the whole self-concept of people with LD, who participated in integrated programmes was found to be higher than of those who participated in segregated programmes (Duvdevany, 2002).

Additionally, most of the past research concerned with the study of self-concept of people with a mild LD used self-concept tests standardized for the general population (for reviews see Schurr *et al.,* 1970; Gowans & Hulbert, 1983). The results of this psychometric approach are commonly translated into quantitative statements about the

location of the self-concept of people with a mild LD on a continuum from 'positive' to 'negative'. Since such scores are purely external to the person whose self-concept is so measured, they are uninformative. They do not help one to understand internal processes of the individuals. Neither do such scores enable one to understand the stigma imposed by the society on individuals with LD.

The classic work of Edgerton (1967) employed participant observation in order to study the lives of people with LD, who had moved out of an institution into the community. In a subsequent paper, Koegel & Edgerton (1982) investigated a group of black Americans who had recently left a school for people with a mild LD. The investigation strategies were based on some of Goffman's (1963) key concepts. The main concern of these studies was to identify their reactions to stigma . In the former study, Edgerton argued that people with a learning disability 'denied' their 'handicap', while in the latter study the authors divided the group into those who 'denied' or avoided the topic, and those who declared themselves as 'handicapped'. Zetlin and Turner (1984) produced a more extensive typology of how the participants coped with stigma, and related the 'type' of response to features of the participants' backgrounds and circumstances. The crucial elements identified by these authors in determining how the participants dealt with stigma were the attitudes and socialization practices of their parents. Although these studies made a valuable contribution to the understanding of the meaning of stigma for people with LD, they did not attempt primarily to gain insight into the relationship between the experience of stigma and the self-concept. More light has been thrown on this issue by case studies presented by Flynn & Knussen (1986) and the autobiographies collected by Bogdan & Taylor (1982). However, although these studies vividly convey the feelings and experiences of people with a mild LD, they have the drawback of remaining essentially descriptive. Jahoda, Markova and Cattermole (1988) tried to gain as much understanding as possible into the experience of people with LD and into the nature of their self-concept by combining two rather different approaches: the phenomenological and the quantitative. It was found that all participants with LD were aware of the stigma attached to them, of their own agency and clearly expressed their socio-emotional needs.

Furthermore, according to Finlay and Lyons (1998), people with learning disabilities in Britain might be expected to experience a negative social identity. They are less likely to achieve socially valued goals such as living independently, having a career or succeeding in school. Negative evaluations of people with learning disabilities continue not only in terms of ability levels, but also in terms of moral and social traits (Mittler, 1984; Eayrs et al., 1993; Hastings & Remington, 1993). Research has shown that people with learning disabilities are usually aware of these negative social evaluations (Szivos & Griffiths, 1990; Sinason, 1992). Researchers such as Sinanson (1992) have reported that individuals with LD are often aware of the negative concept that society has of them and which they can end up sharing. Gibbons (1985), supported further this argument and concluded that this population may share these negative evaluations implied in their labelling. Social comparison plays an essential role in the development of self-esteem, as people evaluate themselves in comparison with other people. Within this framework, any negative information derived from this process, because of significant limitations in intellectual functioning or in any of the adaptive skills, will constitute a threat to their self-esteem. Studies on self-concept and self-esteem of individuals with mild-borderline learning disability reveal contradictory results. In some of these studies, young and adult disabled people obtain significantly lower scores in self-concept and self-esteem than do people who are not learning disabled (Facchini, 1996; Long, 1997; Masi, Mucci, Favilla, & Poli, 1999; Szivos & Griffiths, 1990). This is not surprising if we take into account the customary limitations these people present in various conceptual, social, and practical adaptive skills. However, in other investigations, the opposite is observed, that is, an exaggerated appraisal of self-concept and self-esteem in people with mild-borderline learning disability (Li, Tam, & Man, 2006; Repetto, & Cifuentes, 2000). In accordance, some authors emphasise that the concept that people with mild learning disability have of their disability may have such a strong emotional charge that it makes them incapable of admitting and accepting their limitations. Thus, they may feel the need to protect themselves from negative appraisals and to compensate themselves through excessive appraisals of their self-concept and self-esteem. Being aware of their many difficulties, they may come to reject attributions of inferiority or incompetence, developing a denial mechanism (Gresham & MacMillan, 1997; Repetto & Cifuentes, 2000; Garaigordobil &

Pérez, 2007). In short, another finding revealed that individuals with learning disabilities often either denied the label applied to them or do not mention it (Finlay & Lyons, 1998).

However, there has been remarkably little research on the impact of being categorized as a person, who has learning disabilities. As Beart, Hardy and Buchan (2005) explain: "while entire services are set up around this categorization we have little information on the impact of this social identity on people and how it informs and shapes their sense of self"(Hardy and Buchan, 2005, p. 48).

6. Home and Place

6.1. Place Identity

Place identity is a concept that refers to people's bonds with places. Proshansky defines place identity as 'those dimensions of self that define the individual's personal identity in relation to the physical environment' (Proshansky , 1978, p. 147). This finds expression within individuals' preferences for or sense of emotional belonging to particular environments. It takes the form of a ''psychological investment with a setting that has developed over time'' (Vaske & Corbin, 2001, p. 17) and that is captured in the everyday phrases such as feeling 'at home' or having a 'sense of place'. These processes of familiarity and attachment underwrite a third component of place identity, which concerns how material environments may come to express or symbolise the self. The most obvious illustration of this process concerns the personalisation of the home, as enacted, for example, through the décor, design and the everyday use of residential dwellings.

The word ''identity'' means two things (Jacobson-Widding, 1983): sameness (continuity) and distinctiveness (uniqueness), and therefore the term 'place identity' should incorporate both aspects. The concept of 'identity', when applied to a place, may carry two altogether different meanings. The first meaning of 'identity'refers to the term 'place' and means a set of place features that guarantee the place's distinctiveness and continuity in time. According to Twigger-Ross and Uzzell (1996), place is a means to

distinguish oneself from others, to preserve a sense of continuity, to build a positive self-esteem, and to create a sense of self-efficacy. In analogy to place attachment (Low & Altman, 1992; Hidalgo & Hernandez, 2001), bases for place identity may differ in scale. One may feel foremost a resident of a 'city district', city, country region, country, continent, or even a 'citizen of the world' (Lewicka, 2008).

7. Effects of Involuntary Relocation

Residential transition entails changes in physical surroundings and social relationships, as well as, changes in occupation pursuits, leisure activities, expectations and basic daily functions. These disruptions in daily living and social patterns require major readjustments that may be stressful to the individual (Heller, 1982). Fried (1963) and Parkes (1972) compared reactions to loss of loved ones to reactions to involuntary residential relocation. They noted that such moves were often accompanied by grief symptoms, 'feelings of painful loss, continued longing, general depressive tone, frequent symptoms of psychological, social and somatic distress, sense of helplessness, occasional direct and displaced anger, and a tendency to idealize the lost place' (Fried, 1963, 151).

On the other hand, relocation to a new environment may have positive effects by facilitating changes in individual, social and intellectual functioning. For instance, Kelly (1968) supported that experience in a fluid environment provides more exposure to diversity and enhances adaptation to complex and changing future environments.

8. Moving Home and People with Learning Disabilities

8.1. The Lives of People with Learning Disabilities

The majority of people with learning disabilities reside in the family home until carers are no longer able to support them. It is estimated that around 60% of adults with learning disabilities live with their family, with a third of these living with a carer over the age of 70 (Mencap, 2000). In the past the only other care option for an individual with learning

disabilities was to be placed in an institution. Such institutions were set up under the eugenic movement, led by Sir Francis Galton, which believed that people with learning disabilities should be stopped from multiplying (Howard & Hendy, 2004). The conditions under which residents lived, however, were poor, and hospital scandals in the 1960s and 70s (DHSS 1969, 1971, 1978) exposed shocking settings and abuses. At around the same time, pressure from parental groups to give people with learning disabilities the right to an education, forced the government to pass the 1970 Education Act, which pledged that all children should receive an education regardless of their (dis)ability.

In 1971 the Department of Health White Paper 'Better Services for the Handicapped' pushed for the development of smaller-scale residences in the community for people with learning disabilities. Since then, the large institutions have been gradually shut down. There was a hope that this would improve the quality of life of people with learning disabilities, and increase the opportunities available to them. However, despite these changes, the Department of Health acknowledged in its 2001 White Paper that people with learning disabilities are still one of the most marginalised groups in our society. As a result, emphasis has been placed on the importance of promoting inclusion, choice, independence and civil rights in the lives of people with learning disabilities.

8.2. Transition to Adulthood for People with Learning Disabilities

According to Brammer, transition is 'a sharp discontinuity with previous life events' (Brammer , 1992, p, 240). Throughout their lives, people encounter a series of transitions, in which they are forced to adapt to changing circumstances. This involves events such as leaving school, going into education or work, learning to drive, and being legally able to vote, drink alcohol and marry. For many, it also involves leaving home. However, for people with learning disabilities, this transition is often not fully realised, and for many it is delayed for an indefinite period.

Baker (1991) discussed extensively the reasons the transition to adulthood may be postponed in people with learning disabilities. He claims that usually the process of

independence and separation from parents is a process initiated by the young person, rather than the adults around them. As they grow older, children begin to form their own identity, and in doing so, they start to challenge their parents. This process allows the child to become more independent and assertive. People with learning disabilities find it difficult to achieve assertiveness and parents hesitate to give independence to the young person. In order for competence to be achieved during the process of individuation, it is important for the child to be able to experiment, to make choices about risks, and to learn from mistakes (Field, Hoffman & Posch, 1997). Again, this is not always possible for people with learning disabilities, and as a result the transition to adulthood may not be completed. Surprisingly, despite the recognition of the difficulties involved in making a successful transition to adulthood, few studies have explored the views and experiences of people with learning disabilities during such times.

8.3. Moving Home

One of the transitions experienced by many traditional Western families is when adult children grow up and leave the family home (Carter & McGoldrick). However, for young people with learning disabilities moving home may be delayed considerably or may not happen at all. The majority of people with learning disabilities is being taken care within the family home by relatives, but as people with learning disabilities are beginning to outlive their parents, a placement outside the home into supported accommodation may become necessary.

Often people with learning disabilities in supported accommodation have little choice or control over their lives. However, when comparing such residential services to family settings, research has shown that although people with learning disabilities who live at home receive considerable support from family members, they also tend to use fewer services, have fewer friendships with people of their age, and are more likely to be obese. They are also at risk of experiencing an emergency transition into residential services, if advanced planning for future care does not occur (Seltzer & Krauss, 2001). These findings suggest that people with learning disabilities who live within the family home

may be isolated and take part in fewer activities than those living outside the home. This may reflect the lack of opportunities for them to become more independent and assertive.

8.4. Types of Housing

Several different types of residential services are available to people with learning disabilities when moving out of the family home. Various terms are used to describe such housing. These include:

- Residential care homes/ hostels - Relatively large homes (of up to 30 people) for people who need substantial support. Staff is typically present at all times to help out with shopping, housework, cooking, personal hygiene etc.

- Group home – A small flat or house in which a small group of people lives together. Staff visits the house to help with cooking, shopping and housework and sometimes stay overnight.

- Living in care /living with another family/adult placement/supported lodging – Sharing a house with the rest of a family with support provided as and when required.

- Supported living networks/living in cluster housing/ sheltered housing– When a group of people lives near each other in the same neighbourhood, street or block of flats. Each person has their own separate house or flat but knows and meets up with others in their area regularly. Usually individuals living in this kind of accommodation predominantly care for themselves, and a support worker or a keyworker helps with tasks such as accessing benefits and paying bills. (The Foundation for People with Learning Disabilities, 2001)

8.5. Reasons for Moving Out of Home

Essex, Seltzer & Krauss (1997) investigated the factors that facilitated residential transitions and found three transition profiles:

- Normative launching: the person with a learning disability moved out of home at about the same time and for similar reasons to most non-learning disabled people

- A move as a coping mechanism in response to stressful circumstances: the transition was precipitated by difficult events or situations

- Postponed launching: a move occurred much later in life as a precautionary strategy in preparation for the time when the carer would no longer be able to cope.

Alborz (2003) interviewed 18 carers of people with learning disabilities who had recently made the transition from the family home into residential services and found that transitions fitted into these three profiles. The majority of moves (78%) were due to stressful circumstances and Alborz suggested this profile should be extended to incorporate three types of stress moves – forensic (involving actual or near intervention by the police), family (problems such as parental ill health or marital breakdown) and service (lack of service provision).

8.6. Planning the Move

A high proportion of moves in response to stressful circumstances, as they are reported in the study by Alborz, highlights the need to plan residential transitions in advance. Not only can emergency moves be highly distressing for the service user and those around them, but they also inevitably lead to less choice and control over future accommodation as service users are limited to what is available at that moment in time. Forward planning can increase the amount of choice and control for service users and their families about how and where they live, an issue that has been emphasized in the Department of Health's (2005) consultation paper entitled Independence, Wellbeing and Choice.

However, research has shown that most families avoid planning. Several studies revealed that carers were reluctant to make concrete future plans (Prosser, 1997; McConkey, McConaghie, Barr & Roberts, 2007; Gilbert, Lankshear & Peterson, 2008). This issue appeared to be compounded by poor communication between the housing and social work departments (Bowey & McGlaughlin, 2007). Reasons given by carers for this reluctance included a perceived lack of a need due to the presence of two carers, a lack of

knowledge of the housing options available and the timescale required to secure housing, feelings of guilt and difficulties in letting go, and the presence of mutually supportive relationships.

The above studies also examined reasons that seemed to increase the possibility of making plans. These included greater contact with friends and family (Kaufman, Adams & Campbell, 1991), being a single carer, caring for someone with behavioural problems (often linked to a higher caregiving burden), and having a child with mild or moderate as opposed to severe or profound learning disabilities (Freedman Krauss & Seltzer, 1997). The presence of a reciprocal caring relationship has been reported by several researchers (e.g. Walker & Walker, 1998; Grant, 1986), and appears to result in a reduced probability of making future alternative housing plans. This mutually dependent relationship is likely to become more significant as the carer ages and comes to rely on the service user more for support. Bowey & McGlaughlin (2007) also found that families' experience of respite services also affected their willingness to plan for the future. For example, having short breaks acted as a 'preparation tool' for LD people to experience time away from family members, while it also gave families an insight into services.

9. Research Studies on Moving Home, Identity and Learning Disability

Although several studies have explored how families plan for residential transition from the family home, few studies have looked at the experience of moving home and its impact on the individual with learning disabilities and his/her identity. As noted earlier, transitions can signify difficult times. The transition of moving away from home can be a difficult experience for anyone, but for people with learning disabilities it can be particularly challenging, especially if precipitated by a stressful event, as often appears to be the case for people with learning disabilities.

Alborz's (2003) study did examine the process of transition, but this research primarily focused on identifying the precipitating causes for the transition rather than the experience of the transition itself. Moreover, it only interviewed carers rather than service users themselves. Bigby (1996) explored people's experience of transition into residential

services, but this Australian study focused primarily on the presence or absence of plans preceding the move. This is one of the few studies, however, which involved interviewing service users, as well as, carers and service providers.

Other research has explored the extent of family involvement in the care of their child after a move to residential services has been made. Baker & Blacher (1993) found continuing family involvement to be very high two years after a child with learning disabilities moved away from home. Most of these pieces of research were quantitative in nature and did not explore the participants' experiences of transition in depth. The studies by Alborz and Bigby did use qualitative analysis to explore perceptions of transitions, but these studies focused on reasons or transitions and plans rather than the experience of the transition itself. Few studies have been conducted from a psychological perspective, grounding the findings in psychological theory and understanding.

Cattermole, Jahoda and Markova (1988) conducted a study with 12 people with learning disabilities, who had left the parental home in order to live in community residential hostels. This study involved people with learning disabilities, parents and hostel staff. It was found that social life, autonomy and opportunities to develop self-help skills had been limited at home. The individuals who had the widest social experience and the greatest use of self-help skills at home were the most active in changing. This study did not concentrate so much on people's identities and on their moving experience but gave an insight into what the participants gained out of moving home.

Tsiantis et al. (1995) conducted a study on the deinstitutionalization and rehabilitation of 11 people with severe learning disabilities from a psychiatric institution at Leros island in Greece to a community home in Athens. They discussed how the resident care and adaptive behaviour started to improve and how the communication between the residents and their families increased. However, no information was given around the impact of this transition on the identity of these people.

There were also a number of studies conducted around the quality of life of people with learning disabilities after leaving hospitals and moving in the community. All these studies showed improvements in the lives of this population (Cullen et al., 1995; Maisto & Hughes, 1995; Dagnan, Ruddick & Jones, 1998; Ager et al., 2001), but failed to discuss the experience of moving home for this population.

Owen, Hubert and Hollins (2007) conducted a study with 11 women with intellectual disabilities who had lived in a locked ward of an old intellectual disability hospital and who were moved to the community when the ward was closed down. The study found that the experience of the move was largely negative for all the women: they were not involved in the process of their move, little information was transferred to their new homes and were insufficiently supported. The study also found that for the majority of the women little changed in their lives in their new homes. The study found that, in general, these women continued not to be acknowledged as unique individuals, who have pasts, close relationships, clear preferences, abilities and rich emotional lives. Although a valuable contribution to the field, this study did not make links to participants' identities and moving home.

Jones (2010) explored the experience of moving out of the family home for African Caribbean people with learning disabilities. She conducted six semi-structured interviews with African Caribbean people with learning disabilities who had moved out of the family home and the interviews focused on their experiences of residential transition. The data was then analysed with the use of Interpretative Phenomenological Analysis. Both an individual and group analysis was carried out in order to ensure that individual voices were heard. The group analysis produced three super-ordinate themes. The first, 'struggle', described participants striving for empowerment and autonomy whilst feeling frustrated by their dependency and powerlessness. The second, 'connectedness', described participants' repeated experiences of loss and rejection and their desire to form close relationships and belong to a wider community. Finally the third, 'appraisal with emotion', described participants' anxieties regarding residential transitions in terms of their perceived vulnerability and limited resources, as well as, a sense of hope about the

future. Although this study gave significant insights into the experience of moving home, it did not explore the impact the moving process had on the identity of participants.

Jahoda and Markova (2004) conducted a phenomenological study of 10 individuals with learning disabilities moving from their family home to live more independently and 18 moving from a long-stay hospital to live in community housing. Researchers found that all participants felt stigmatized and were aware of the stigma associated with learning disabilities. Participants regarded themselves as part of a minority group who rejects prejudice and attempts to distance themselves from stigmatizing services and from other people with learning disabilities. This study shed some light into the impact residential transition has on the identity of people with learning disabilities, but merely focused on exploring stigma and not on investigating any other aspects of the participants' moving experience connected to their identity.

There is therefore a need for further research to be conducted, which explores the experiences of people with learning disabilities when moving from the family home into a care home and its impact on their self concept. This research will address this need and will fill in an existing gap in literature. The findings will help Counselling psychologists become more aware of the impact of residential transitions on the identity of this particular population. On a wider scale, this research wishes to have a direct impact on policy-making and services and hopes to provide examples of good practice and clinical recommendations.

10. The Role of Counselling Psychologists in Supporting People with Learning Disabilities through Moving Home

The role of counselling psychology in the lives of people with learning disabilities often takes place within the context of the family or community services. Counselling psychologists often find themselves working not only on an individual basis with the person with learning disabilities, but also on a more systemic level in order to enhance

family relationships. The stress and burden of care giving within the family home can have a huge impact on family members and on their psychological wellbeing. The 2001 Department of Health report entitled 'Family Matters', highlights how the emotional wellbeing of carers is jeopardised by feelings of isolation and loneliness. It is often at the point of transition that individuals and families experience intense stress. Counselling psychologists can intervene to assist the client in managing the stress and in coping with the change and/or with its impact in the client's life.

Counselling psychologists, along with other professionals, can also become involved in the process of moving home in terms of assisting service users in the process of making decisions. This inevitably places them in an influential position since the decisions made have the potential to dramatically change the lives of clients and their families. Understanding more about the experiences of people with learning disabilities during and after times of the move could prove to be highly informative and helpful for all related professionals .

11. Research Question

In the light of the above discussion, this research will attempt to provide an answer to the following question:
What is the impact of moving home on the identity of people with learning disabilities?

12. Chapter Summary

In relevant literature on people with learning disabilities, moving home was often associated with their deinstitutionalization (Collins, 1992; Emerson & Hatton, 1994; Aspray, Francis, Tyrer & Quilliam, 1999; Robertson et al, 2004), adaptive behaviour skills and their social integration into the community (Ager, Myers, & Kerr, 2001). This transition, although not an easy one, aimed at improving the quality of life and the future of this population (Ericsson & Mansell, 1996; Dagnan, Ruddick & Jones, 1998; Forrester-Jones, Carpenter, Cambridge, Tate et al., 2002). However, past research rarely focused on the impact this moving has on the identity of people with learning disabilities.

Moreover, most research studies focused on the transition from the institution to the community or to the supported living and not on the transition from the family home. There were few studies conducted from the perspective of the learning disability population itself. This research study aims to address these gaps in the area of moving home, learning disability and identity.

13. Chapter 2 - Methodology and Procedures[4]

14. Methodology

14.1. Chapter Overview

The present chapter discusses the rationale for using Interpretative Phenomenological Analysis (IPA) in this research study by discussing the epistemological position of the researcher and the relevance of IPA for the explored research area. In conclusion, I will present an overview of the methods and the procedures used in the current study.

14.2. Research Design

This research study has employed a qualitative research methodology. I collected the data by conducting semi-structured interviews on a small homogeneous sample. The data was subsequently analysed with the use of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009).

14.3. Research Rationale - Definition of the Research Question

In the current literature, there are few studies that have been conducted about people with learning disabilities changing home. Most of these studies focus on the quality of life of residents and employ quantitative research methods in order to identify variables that are associated with service users' satisfaction and with factors affecting adjustment and/or behaviour. There is also a number of both quantitative and qualitative studies focusing on the experience of staff in residential settings and a number of documents with practical advice preparing people with learning disabilities who move home. As I have discussed previously, this existing gap in literature makes it rather urgent the need to gain a more in-depth understanding of the impact of changing home on the identity of people with learning disabilities from their perspective. Hence, my decision to focus only on people

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[4] This chapter is written mostly in the first person so that the reader is addressed directly when the research stages are described and in order to demonstrate reflexivity.

with learning disabilities and not on both people with learning disabilities and the service staff or their family so that I give them voice and take the insider's perspective.

The overall aim of this research was to investigate the impact of change on the identity of people with learning disabilities. In other words, how the change from a family home to a care home can influence the identity of a person with learning disabilities. More specifically:

- To identify what is understood by change of context e.g. home
- To explore feelings and emotions that are often associated with this change
- To explore the experience of change from the family home to a care home
- To discuss change of home from a personal perspective
- To identify changes in self-concept/ personality, if any, after the change of home
- To discuss how one perceives his/her social identity after this change
- To identify coping mechanisms or personal support mechanisms that might have been developed with this experience.

Willig (2001) supported that everyone retrieves different resources that are influenced by their experiences, their historical background, or their social milieu. Reality, therefore, can be constructed in many different ways, depending on the resources that each individual uses in each situation. Participants' accounts of this study would be part of the reality that the researcher aims to understand. This study is concerned with the subjective nature of this particular phenomenon and it attempts to explore the beliefs and feelings that the individuals bring to the experience. In particular, this study tries to investigate the meaning they attach to this phenomenon by considering the way this experience has affected the way they perceive themselves.

Since the aim of the research is to explore the meaning of the participants' experience, it seemed appropriate to use a research methodology that would enable such exploration. Qualitative methodologies regard researchers as participating in the process of data generation (Smith, 1996) and reflexivity is an integral part of qualitative research (Pillow, 2003); both characteristics can also be found in the practice and principles of counselling

psychology (BPS, 2005). Therefore, the adoption of qualitative methodology is also congruent with the researcher's role as a practitioner. The semi-structured interviewing was chosen as a means for the collection of data. Qualitative research methods regard interviews as essential for obtaining scientific knowledge (Kvale, 1996). The goal of qualitative research methods in psychology is to develop an in-depth understanding of a particular phenomenon, based as much as possible on the participants' perspective (Elliot, Fischer & Rennie, 1999).

14.4. Choice of Methodology

14.4.1. Rational for Choosing IPA

IPA is often seen as a qualitative research method that is notable and preferred for its accessibility, flexibility and applicability (Larkin, Watts, & Clifton, 2006). IPA is characterised by a flexibility and openness in terms of procedure and levels of interpretation that allows the data to guide the research process. Therefore, IPA methodology seemed to be the most appropriate for this research study, which endeavours to shed light on the experience of moving home for the participants, what it meant to them and how it affected their identity. I was confident this methodology would assist and enable participants to talk about their process of change and how they managed this experience.

Furthermore, since the main focus of this research was participants' sense of their identity IPA was the most appropriate analytic strategy to employ in order to explore identity and the experiencing of the self as a whole entity (Smith, 2004). IPA is frequently employed in research conducted around identity changes linked to major life transitions and due to the existential flavour of qualitative studies, it is not surprising that participants connect the topic of concern to their sense of self (Smith, Flowers & Larkin, 2009). In this study participants spoke extensively about themselves in relation to changing home.

Additionally, IPA's links to phenomenology (see section on *Overview of IPA)* permits the participant and the researcher to look into their own process in a reflexive way. The

process of looking into one's self and identity require reflexivity and this was also the case for this research study. Choosing IPA, therefore, seemed to be appropriate for this reason.

Another reason for choosing IPA was the increasing interest in carrying out IPA with different groups. There is a variety of studies on the learning disability population that employ the IPA methodology (MacDonald, Sinason, & Hollins, 2003; Ditchfield & Burns, 2004; Baum & Burns, 2007; Wheeler, 2007) and that has informed my decision for choosing IPA for my population. Smith (2004) supported that IPA guidelines in terms of conducting the interviews would need to be adapted to the population. He suggested that the learning disability population may require the researcher to assume a stronger role guiding them in the interviews. Additionally, I thought I could draw from my clinical experience with clients with learning disabilities in order to 'modify existing protocols when collecting data' (Smith, 2004, p.49).

IPA also focuses on meaning-making and sense-making by both participant and researcher (Smith & Osborn, 2003) and since this study aimed at exploring the meaning participants made of their experience of changing home, this methodology was deemed most appropriate. IPA can also be very useful when a researcher is concerned with novelty (Smith & Osborn, 2003). Changing home from the perspective of people with learning disabilities was a novel research topic and I considered that IPA would serve it adequately.

Instead of using IPA, another option for this study would be to use Grounded Theory. Grounded Theory and IPA share many common features. Both approaches aim to produce a cognitive map of a person's world view and both start with individual cases which are then integrated to obtain a composite picture of the phenomenon (Willig, 2001). Their difference is that Grounded Theory's goal is to identify and describe contextualized social process which account for phenomena, while IPA focuses on gaining a better understanding of the quality and the texture of individual experiences and on gaining an insight into individual's life world (Willig, 2001). If this study aimed to

develop a theory about people with learning disabilities changing home, Grounded Theory would be particularly useful. However, this research study aimed to take a more exploratory approach investigating moving home as a novel experience for people with learning disabilities. IPA, therefore, would enable designing a tentative model that can give insight into participants' experience of moving home, in the format relationships between emerging themes from participants' accounts (Smith, Flowers & Larkin, 2009).

A further option for this study would be to use phenomenology. Despite IPA's links to phenomenology, IPA differs from phenomenology in some ways. Phenomenology involves the use of thick description and close analysis of lived experience to understand how meaning is created through embodied perception (Sokolowski, 2000; Stewart & Mickunas,1974), whereas IPA involves the use of interpretation. In IPA one is trying to get close to the participant's personal world, to take, in Conrad's (1987) words, an 'insider's perspective', with a two-stage interpretation process, or a double hermeneutic (see section on *Overview of IPA*, p.61*). Different interpretative stances are possible, and IPA combines an empathic hermeneutics with a questioning hermeneutics. Thus, consistent with its phenomenological origins, IPA is concerned with trying to understand what it is like, from the point of view of the participants, to inhabit their position. At the same time, a detailed IPA analysis can also involve asking critical questions of the texts and narratives of the participants (Smith & Osborn, 2003). Therefore, I chose IPA for its two-stage interpretation process, since I considered that this would allow me an 'insider's perspective.

Furthermore, it is important to note the differences between phenomenology, grounded theory and IPA in the process of analysis, since some minor differences that distinguish the three analytical processes have determined my decision to choose IPA as my methodology. In phenomenology there are three distinct phases of contemplation to derive the essence of phenomena: 1)Epoche (where assumptions, judgments and interpretations are suspended, 2) Phenomenological reduction (where the phenomenon is described in terms of colour, texture, shape, and size, as well as, in terms of thoughts and feelings), and 3) Imaginative variation (structural components of the phenomenon to

identify the conditions associated with it e.g. space, time, social relationships) (Willig, 2001). Phenomenology requires intense reflection as a fundamental part of the process, but above all, the primacy of the subjective experience is felt to be crucial. Analysis is conducted by scrutinising the text for meaning "units" which describe the central aspects of the experience. These are then combined to provide a general description of the "whole" (Goulding, 2005). On the other hand, grounded theory involves a constant comparison method of coding and analyzing data through three stages: open coding (examining, comparing, conceptualizing, and categorizing data); axial coding (reassembling data into groupings based on relationships and patterns within and among the categories identified in the data); and selective coding (identifying and describing the central phenomenon, or "core category," in the data) (Dey, 1999; Strauss & Corbin, 1998). Ideally, each interview or observation is coded before the next one is conducted so that new information can be incorporated into subsequent encounters. Themes identified through the coding of initial interviews may also be explored in follow-up interviews (Starks & Trinidad, 2007). Although IPA and grounded theory are similar in the analytical process, IPA tries to understand the content and complexity of meanings rather than measure their frequency. This means that the researcher has to engage in an interpretative relationship with the transcript. While one is attempting to capture and do justice to the meanings of the participants, those meanings are not transparently available; they must be obtained through a continuous engagement with the text and a process of interpretation. Hence, the method adopted by IPA is a cyclical process, where the researcher proceeds through several iterative stages: in Stage 1 there is the first encounter with the text that involves taking unfocused notes which reflect initial thoughts. In Stage 2, preliminary themes are identified per individual or interview. In Stage 3, themes are grouped together as clusters to reflect wider concepts or shared meanings. In Stage 4, themes are tabulated in a summary table for each respondent with illustrative quotes (Willig, 2001). This scheme can be applied to a single text. However, IPA is frequently used and applied in more than one transcript, journal etc. The researcher can use the master list of themes obtained from the first interview to identify more instances of these themes in subsequent interviews, while also being alert to the possibilities of new themes. A second approach is to start the whole process afresh with the second or subsequent

interviews and produce a different list of themes for each interview. These themes are then drawn together into a consolidated list. Then we proceed to an integration of summary tables for each respondent, where master themes indicate shared experiences. Whichever path is chosen, the process is cyclical. New themes are tested against earlier data. In the light of later findings, the researcher may need to modify the thematic analysis. Themes may become either subordinate or super-ordinate to themes found earlier (Biggerstaff & Thompson, 2008). I felt that the use of a cyclical interpretative process in the data analysis would assist me in my meaning making of the participants' accounts.

Therefore, IPA was deemed more appropriate to meet the aim of this study, which is to gain an insight into the experience of changing home for people with learning disabilities and its impact on their identity.

14.4.2. Overview of IPA

Interpretative phenomenological analysis (IPA) is 'concerned with the detailed examination of individual lived experience and how individuals make sense of that experience' (Eatough, & Smith, 2008, p. 179). IPA was created by Jonathan Smith only in the mid-1990s as a specific approach to qualitative research (Smith, J.A., 1994, 1996). IPA has underpinnings in phenomenology and hermeuneutics and relates to the field of psychology in the area of subjective experience and personal accounts, as supported in the works of James in 1890 and Allport in 1953. An essential factor for the growth of IPA was the expression of a 'qualitative approach to psychology which was grounded in psychology' (Eatough & Smith, 2008, p. 180). IPA has been applied often in psychology research, especially in the areas of health, counselling, clinical, social and occupational psychology (Smith, 2004).

Smith (2004) supports that IPA has three elements in general. It has an epistemological position, it provides a number of guidelines for doing research and portrays a body of empirical research.

IPA is phenomenological in nature, since it investigates people's perceptions of events. IPA operates within phenomenology and in the context of psychology. It is preoccupied with human lived experience and speculates that experience can be understood through an examination of the meanings which people attribute to it. People are physical and psychological beings; 'they do things in the world, they reflect on what they do, and those actions have meaningful, existential consequences' (Smith, Flowers & Larkin, 2009, p.34).

A particularly appealing side of IPA lies on its interpretative nature. IPA is interpretative, since the analysis always involves interpretation (Smith, Flowers & Larkin, 2009). IPA has to adopt an 'insider's perspective' and acknowledges this research experience as a dynamic process. Even if the aim of IPA is to get close to one's social world, this is influenced by the researcher's own thoughts and experiences, which are needed in order to interpret this other personal world (Smith, 1996). This interpretative process is accurately described by Heidegger's notion of 'appearing'; that is, a phenomenon is ready to emerge, but the researcher needs to do finding-out work in order for this to appear and after its appearance the researcher needs to make meaning out of it. This research process is circular and it is referred as the hermeneutic circle (Smith, Flowers & Larkin, 2009). During the process of analysis, IPA involves a double hermeneutic (Smith & Osborn, 2003): 'the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world' (Smith, 2004, p. 40). IPA tries to understand the participant's point of view and takes their side, and it can also ask critical questions from the participant. There is, therefore, a double meaning in the 'understanding' that the IPA researcher aims to do: the one aspect involves identifying and empathizing with the participant and the other involves making sense of the participant's position and meanings. IPA in this case is influenced by symbolic interactionism, in its attempt to make sense of the world of the other (the personal) in the context of the world (the social) (Smith & Osborn, 2003). It is important to add that there are different levels of interpretation in IPA. An analysis will progress through different levels of interpretation until it sinks to a deeper analysis, grounded in the encounter of the researcher and the

data. A successful interpretation is based on a reading from within the data generated from the participant (Smith, Flowers & Larkin, 2009).

IPA is characterised by three main features: it is idiographic, inductive and interrogative (Smith 2004). IPA is idiographic because it focuses on a particular case rather than a general population. As Smith, Flowers and Larkin (2009) claim, 'only through painstakingly detailed cases of this sort can we produce psychological research which matches and does justice to the complexity of human psychology itself' (Smith, Flowers and Larkin, 2009, p. 38). IPA's idiographic feature operates on two levels: first, the researcher that conducts IPA is committed to the sense of detail and to the depth of the analysis, which is systematic and thorough. Later on, the IPA researcher aims to understand how specific events have been understood from the viewpoint of particular people, in specific circumstances (Smith, 2004). Subsequently, small, purposively-built and mindfully-situated samples are used in the analyses (Smith, Flowers & Larkin, 2009). IPA examines in detail a single case and then moves to analyse in detail a second one, and so on, and only when a degree of closure has been achieved in all cases, then it conducts a cross-case analysis of all of them, in order to identify common themes. With this process, IPA's 'delving deeper into the particular also takes us closer to the universal' (Smith, 2004, p. 42), which means that examining details of each individual case helps us to come closer to forms of shared experiences with all people, to aspects of the general (Smith, Flowers & Larkin, 2009). This idiographic aspect of IPA is closely connected to Husserlian phenomenological psychology (Giorgi & Giorgi, 2003). Husserl argued that we should go back to the things themselves and that process involves departing from our everyday experience, our natural attitude, so that we can examine everyday experience. This requires the IPA researcher to adopt a phenomenological attitude, a reflective stance. He/she needs to 'bracket' 'the taken-for-granted world in order to concentrate on our perception of that world' (Smith, Flowers & Larkin, 2009, 13). Husserl's thinking has helped the IPA researcher to concentrate on reflection. However, while Husserl intended to find the essence of experience, IPA focuses on lived experience and on particular actual life cases (Smith, Flowers & Larkin, 2009).

In addition to its idiographic nature, IPA is inductive. That means that it involves flexible techniques in order to permit unexpected subjects or themes to emerge during analysis. It does not focus on specific hypotheses but rather on broad research questions that bring forward a vast amount of data. Here we need to highlight that the research process involves both inductive and deductive elements; however, IPA follows primarily an inductive reasoning (Smith, 2004). Examples of inductive IPA analysis can be witnessed in Smith (1999).

IPA is also interrogative. After an extensive analysis of cases, IPA discusses the results of such analysis with the use of existing psychological literature. IPA, therefore, contributes to psychology by illuminating and enriching existing research (Smith, 2004).

A controversial aspect of IPA involves its concerns regarding the field of cognitive psychology and cognition. Smith argued that IPA involves cognition and fits well with a social cognition paradigm. According to his view, a person owns a number of cognitions, which he uses to understand the world around him and to proceed in his daily life (Willig, 2001).

Another aspect of IPA is that it can be particularly suitable for the investigation of novel topics such as health and illness, sex and sexuality, psychological distress and life transitions and identity. Much IPA work is done around identity changes related to significant life transitions. This is expected if a research topic has a considerable existential moment. It is very likely that the participant will relate the topic to his/her sense of identity (Smith, Flowers & Larkin, 2009). Therefore, IPA often touches upon issues on identity and the self-concept (Smith, 2004). There is a variety of identity studies available that have used IPA such as Smith's (1994, 1999a, 1999b) on identity change during the transition to motherhood, Timotijevic's and Breakwell's (2000) on how migration impacts on identity, Riggs and Coyle's (2002) on the experience of homelessness in adolescence or early adulthood.

IPA has also been used in studies on the learning disability population e.g. MacDonald, Sinason, and Hollins (2003) investigated the experience of, and satisfaction with, group analytic therapy for people with learning disabilities; Ditchfield and Burns (2004) explored the experience of learning-disabled women in relation to menstruation, and Baum & Burns (2007) looked at the experiences of eight mothers with learning disabilities who lose custody of their children. There is also a variety of studies on identity and learning disability with the use of IPA such as Wheeler's (2007), who explored how a group of men with learning disabilities in South Wales experienced their sexuality and sexual identity.

It is important to note that IPA is often seen as an open and flexible methodology allowing variation on how it is conducted (Larkin, Watts & Clifton, 2006). Both on a methodological and theoretical level, IPA seems to permit a variety of approaches (Langdridge, 2007).

Limitations of IPA will be discussed in the discussion section in relation to this research project (p.161).

14.5. Epistemological Standpoint

The choice of methodology, as well as, the choice of the approach within it is based on the epistemological standpoint of the researcher. Epistemology is concerned with ways of knowing and learning about the social world (Snape & Spencer, 2003). It involves the study of knowledge, the acquisition of knowledge and relationship between the knower-participant and the would-be-knower-the researcher (Ponterotto, 2005). An epistemological paradigm can be defined as "a set of assumptions about the social world which provides a philosophical and conceptual framework for the organised study of that world (Filstead, 1979, 34). The chosen paradigm directs the researcher to philosophical assumptions about the research and to the selection of tools, instruments, participants, and methods used in the study (Ponterotto, 2005). In this section I will attempt to

describe the epistemological standpoint, which I took within this research study, based on research evidence from the accounts of IPA theorists.

According to IPA epistemology, the centre of this research is the lived experience from a personal perspective, 'taking the standpoint of the conscious, thinking, unreflective/reflective, feeling person' (Eatough & Smith, 2008,181). The emphasis, therefore, is not on whether what is reported is considered to be a truthful and accurate depiction in the outside world. I am concerned about the nature of reality and being, but from a constructivist (interpretative) view. I believe that there exist multiple, constructed realities (known as the *relativist* position), rather than a single true reality. Reality is subjective and socially-constructed, influenced by the context of the situation, namely the individual's experience and perceptions, the social environment, and the interaction between the individual and the researcher (Ponterotto, 2005).Consequently, this research study assumes a relativist ontological position and is concerned with completeness rather than accuracy of representations (Willig, 2001). My aim, therefore, was to give voice to my participants and allow them to express fully their experience. Since the learning disability population is usually represented or spoken for, my aim was to give them the freedom of speech without demeaning their accounts by looking for accuracy in their depiction of events.

Furthermore, in line with constructivism, in this study the dynamic interaction between researcher and participant was central in capturing and describing the "lived experience" of the participant; it is through this interaction that the meaning of participant's experiences can be understood. Interpretation plays an essential part in this process (Ponterotto, 2005). Ashworth (2003) defines hermeneutics as the theory of interpretation. Hermeneutics became known from the work of Heidegger(1962), Gadamer (1975, 1976), and Ricoeur (1981) and is constituted of two genres: (1) the hermeneutics of meaning recollection intending to a faithful disclosure of an instance, and (2) the hermeneutics of suspicion aiming to discover behind the analysed experience, a further reality which allows a much deeper interpretation to be made (Scott-Baumann, 2009). According to Heidegger (1962), each person will perceive the same event in a different way, each one

bringing his or her lived experience. We experience a thing 'as' something - it has already been interpreted. For Heidegger interpretation is not an additional procedure: it constitutes an inevitable and basic structure of our 'being-in-the-world' (Finlay & Gough, 2003). In this study I aligned myself with the interpretative position as opposed to a more descriptive position. In line with the IPA approach, I believe that IPA surpasses the mere description of a phenomenon and focuses on what it is like to experience it and what it means for participants to experience it. As mentioned previously this type of interpretative position belongs to the hermeneutics of meaning recollection (Larkin, Watts & Clifton, 2006) and is closer to the aims of IPA, which endeavours to 'work more interpretatively with the data' (Langdridge, 2007, 158). In this study I tried to maintain an interpretative position whilst staying close to the data.

Reflecting more on the interpretative position, I realized that interpretation is frequently used in counseling psychology practice and, thus, could be reflected in research as well. Employing interpretation in order to investigate contextual features of experiences, could be relevant to clinical practice (Svedlund et al., 1994) and can enable the researcher to shed light on hidden features of an experience (Rather, 1994).

Furthermore, this study assumes a social constructionist position. In line with the social constructionist position, sociocultural and historical processes are fundamental in our experience of the world and in our perceptions of our lives (Eatough & Smith, 2008). It is within social contexts that our sense of self and identity are constructed and meanings are communicated. However, one's individuality and sense of self are not lost within social contexts. Through constant reflection, the individual re-evaluates his thoughts and emotions, reconstructs new meanings and makes personal changes (Smith, Flowers & Larkin, 2009).

A particular context plays an important role in how a person understands his/her experience since phenomena happen in a specific place and time, and in a specific cultural context (Larkin, Watts & Clifton, 2006). I took a social constructionist position because I believe that an event can have different meanings in different places and times.

In line with symbolic interactionism (Blumer, 1969), I took a symbolic interactionism stance additionally to my social constructionist position because I believe that human beings derive the meaning of things from their social interactions (shared meanings) and through an interpretative process of modifying those meanings they construct their social world.

Additionally, the use of language has played a vital role in this study. In IPA language plays an integral part in one's social experience of the world. In line with IPA philosophy, people 'negotiate and aim to achieve interpersonal objectives in their conversations and reality is both contingent upon and constrained by the language in one's culture' (Eatough & Smith, 2008, 184). Through their use of language and their choice of words, people express their emotions, thoughts and attitude. In this study the focus was also on the way participants talked about their experiences. However, for IPA communication is not just the language that people choose to use; rather the language is the vessel with which lived experience is expressed and this is evident in the participants' accounts in this study.

14.6. Reflexivity

Within the research process it is understood that the researcher cannot hold a pure objective position. The theoretical orientation, as well as, the experience in the research area will play a significant role in the conceptualisation of the research and the analysis of data (Humlin, 2003). It is, therefore, essential to acknowledge possible influences from the part of the researcher, so that the reader can view the findings within this context (Elliot et al., 1999; Stiles, 1993).

Reflexivity is 'the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes'(Finlay & Gough, 2003, p. 108). Understanding 'other-ness' emerges from making ourselves more transparent. Without reflecting on our own processes we might let our prejudices get in

the way of our research findings (Finlay & Gough, 2003). Reflexivity frequently defines qualitative research. In order to enhance the trustworthiness, transparency and accountability of research, most qualitative researchers will attempt to be aware of their role in the research findings. Their aim is to decipher how their intersubjective experience impacts on data collection, analysis and interpretation (Finlay, 2002a). In IPA, research is a joint product of the participants, researcher and their relationship (Finlay, 2002b) seen through the interpretative eyes of the researcher (Smith et al., 1999). In this study I aimed to keep a constant reflexive stance being sensitive to the way my experiences affect my view of the data throughout the research process. According to Willig (2001), there are two types of reflexivity: personal and epistemological reflexivity and both will be addressed in this section.

14.6.1. Epistemological Reflexivity

A prominent issue in this study was the debate on description vs interpretation with regards to the analysis. Researchers hold different views concerning these two positions. Some view this in a black or white way choosing either a purely descriptive or an interpretative position, whereas others perceive these two positions as part of a continuum with many levels of interpretation.

The descriptive researcher does not need to go beyond the data. Whatever shows up is described exactly as it shows itself. The descriptive researcher is content to describe what is there, however it may be presented (Giorgi, 1992).

Nevertheless, Larkin, Watts and Clifton (2006) supported that in IPA research to simply collect and represent the voices of participants is not enough because it undermines its potential to adequately investigate, comprehend and communicate their experiences and their world views. In their perspective, IPA goes beyond description because it focuses on sense-making activities and our 'involvement in the world'. It offers an interpretative account of what it means for the participant to have this experience and, thus, marches towards interpretation.

However, another viewpoint is that descriptions can be a form of interpretation (Heidegger, 1927/1962) since they attribute meaning. It seems, therefore, that there is a complementarity between these two polarities. Giorgi (1992) attempts to explain it: 'interpretation precedes and surrounds us and is far more prevalent than description, but in situations of basic research, description should have epistemological primacy because of its consistency with respect to evidence' (Giorgi,1992, p. 131). Hence, description and interpretation cannot annihilate each other. Rather, one has to try to understand in very precise ways just how they relate to each other: to stay strictly with the evidentiary 'givenness' of any research situation is to describe; to depart from it for whatever motive means to engage in interpretation' (Giorgi,1992,p. 134).

In this research, I realised that I frequently felt divided between these two approaches. Because of my participants' use of very short sentences, I encountered significant difficulty in extracting themes from the interviews and I was worried about the richness of the data. Thus, I was tempted to be more interpretative. However, I frequently doubted both my descriptions and my interpretations. My position, therefore, shifted a number of times during the process analysis, trying to make sense of my participants' accounts and at the same time trying to stay true to my epistemological standpoint.

My aim in this study was to give voice to my participants and try to not contaminate their experience through my lenses. I wanted to stay close to the data and to my participants' accounts since I believed that as a population, they are not often given the chance to express their views and be acknowledged without others assisting them or getting in the way. In some instances description felt appropriate during the analysis. However, throughout the process of analysis, I could clearly see that there were emotions and underlying thoughts or views that were not immediately expressed and description was not enough. In those instances, I leaned towards interpretation because I felt that in a way participants' voices needed to be explained and interpreted further. I felt that through interpretation their experience could be more elaborated and explained, and my interpretation has been informed by psychological literature and relevant theories. My position, therefore, shifted from one approach to the other. Being guided by the depth of

participants' accounts, I tried to combine these two positions. Overall, I felt that this was a hard and arduous process.

14.6.2. Personal Reflexivity

During my life and my studies in psychology, there was a big emphasis on nomothetic approaches in (psychology) research. My father, who holds a PhD in mathematics had taught me from a very young age the importance of sciences and their validity. This continued in my undergraduate years when my teachers and mentors often favoured quantitative methodologies and suggested their usefulness and contribution to the field of psychology. Therefore, knowledge, for me, was primarily based on quantitative evidence. Later on, this epistemological position was enhanced in my working environment as a practitioner, where my therapeutic effectiveness had to be measured by scales and questionnaires and the numbers would show whether I was a 'good' enough therapist or psychologist.

However, this view that I have been nurtured with, came to be challenged during my training in counselling psychology. As a trainee I realized that a psychologist is both a researcher and a practitioner and that quantitative research is not the only way that phenomena can be explained. As I progressed in my training I had an illuminating epiphany; that as human beings we also carry with us our lived experience, our memories, our views, our identities and these cannot be measured entirely with quantitative methods. My acquaintance with qualitative methodology started then. Since then I have moved from the quantitative approach - that was my background - to qualitative approaches.

Reflecting upon this change, I found choosing qualitative methodology liberating in many ways. I was fascinated by this new field and by the new framework of thinking. However, this change presented me with significant difficulties when conducting qualitative research, in both its preparatory stages (of thinking and preaoaring it) and its later stages (of data analysis). During this research, it was with pain that I realized that my way of thinking and writing was heavily influenced by the nomothetic approach. I

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was trained to explain things and to write in a very formal and quantitative way. It was as if I spoke a different language than the one required in the field of qualitative research. I battled with this by reading more about qualitative methods and how they were conducted, and worked hard to adjust my epistemological viewpoints and ways of thinking. However, writing in qualitative research remained particularly difficult. It felt almost against my own nature - even during writing this study. To overcome this I needed to immerse myself in deep reflection to find the words I needed in order to explain things and to find meaning. This was a more emotive than cognitive process that required from me to be in touch with my own lived experience and to understand it before I embarked on understanding the lived experience of my participants.

During this reflective process I had to consider how my own experiences have impacted upon my analysis and interpretation of my participants' experiences. Inevitably this brought me face-to-face with my own identity. I realised that various parts of my identity may have impacted upon the direction of this study, upon the interview material and the process of analysis. Significant attention was given to aspects of my identity that came closer to those of my participants. I was concerned that my own experiences might direct me to look for and focus on similar aspects in participants' experiences that could mirror or validate my own experience. To avoid the 'seduction of sameness' (Hurd & McIntyre, 1996; Oguntokun, 1998) I made efforts to bracket my own experiences in order to allow those of my participants to come forward in the analysis (Elliott, Fischer & Rennie, 1999). Bracketing is a technique that is frequently used by qualitative researchers in order to not allow their ideas, preconceptions and assumptions to interfere with their attempt to enter into participants' experience. It entails the researcher making a continuous attempt to suspend their prior knowledge about an experience by attempting to bring that knowledge into the surface. It is not possible to be free of bias but as long as we know our bias, we can control its impact (Hayes, 2000).

I can describe myself as a 31-year-old Greek woman living in the UK for 6 years and having moved back to my country of origin in the last two years. I was born in Greece and consider my national identity as being Greek. I came to the UK solely for the purpose

of studies and planned on returning to Greece upon their completion. At the time I started conducting this research project, I considered myself being in the UK on a temporary base and defined myself as a student. I did not see myself as staying in the UK indefinitely. This aspect of my identity allowed me to detach myself from the participants and bracketing these experiences was a manageable task.

However, things became more difficult for me during the years I got my chartered status and found work as a qualified practitioner. I continued to define myself both as a student and as a practitioner. I felt these identities conflicting in some ways.

One aspect of this conflict involved the chartered status. My counselling psychology training towards charteredship had ended and, therefore, I was entering another era of my life where I could practice as a qualified practitioner. Continuing with a doctorate, though, meant that I was still a student and that somehow I had an unfinished business. I felt that my student identity at times was robbing me of my confidence as a qualified practitioner. At the same time my practitioner's identity was not motivating me enough to focus on the doctorate since I already had my chartered status and I was not dependent on the doctorate in order to practice. Furthermore, my student identity reminded me of my temporary stay in the UK, while my practitioner's identity posed the question whether I would stay longer and/or move permanently in the UK.

This constant migration question that had been torturing me was accompanied by various residential moves over the years and finally my migrating back home. At this point I had to be mindful of the residential moves that I experienced prior and during this research study, so as not to assume that these were similarly experienced as those of my participants. This included my feelings about the move and the changes that were occurring. When living in Greece, I moved home once with my family. During my stay in the UK, I moved twice as a student to university halls of residence. This was my first move from my family home to a type of group home. In the halls I had to share the flat with other students as well as the other facilities. Although sharing was familiar to me from home (since I was not living on my own), differences in culture and attitudes made

it harder for me to adjust. I subsequently moved to my own flat living on my own, when my work commitments began. This move signaled a significant change in terms of my identity. This was the first time I lived on my own and for me it felt synonymous to growing up, since I assumed responsibilities I never had before and looking after myself was solely my own task. After moving on my own, I felt ambivalent, unsheltered to some extent but also pleased with the privacy I had, which was non-existing in the halls of residence. I had to be mindful of those feelings emerging when analysing the participants' interviews and to reflect upon how my own process interfered with the analysis.

A significant milestone in my moving history was another sudden and unexpected moving back to my country for approximately 4-5 months due to ill health. At the time, I was not in a physical state to return to London. I felt unsafe, terrified and lost. All my belongings were in London and I felt my life was torn between two countries. After my return to London I stayed for approximately another year on my own flat before I decided finally to return to Greece permanently. This again was a huge life change and the adjustment was difficult. Having no job, I had to move back with my family, where I am currently residing. Living with the parents even in adulthood, if one is single is very common in the Greek culture and parental support at all levels is given willingly. However, I frequently felt dependent and I missed living on my own. I had to develop self awareness, in order to be mindful of my own process and how my material and experiences could affect the research. I felt that the more I became aware of my own process, the more I could bracket my own experience and acknowledge my limitations to do so where that could not be possible.

Additionally, in the middle of the research project my own circumstances changed making me get closer to my participants. My cancer diagnosis, even after the end of treatment, left me carrying the stigma of being a cancer patient. As the population of this study can be frequently stigmatised due to their learning disability, I also felt I was carrying a label. I, therefore, doubted the gap that I had placed between my self and the

participants. I had to be mindful of my own feelings and I constantly questioned whether I attributed my perception of my stigmatised identity to my participants.

Having to take a break from the research process due to health reasons, has also affected my relationship with this research. Coming out from my battle with cancer, I could not remember my material or the analysis that I had conducted. I had, therefore, to revisit the transcripts and conduct the analysis again. As far as the analysis was concerned, this was a long and challenging process. I was constantly reflecting on my interpretations and I struggled with making the specific abstract. I found myself working on this process for a long time, in order to be able to construct a final table of themes that would capture the essence of my participants' experience and at the same time would help others understand it.

Reflexivity allowed me to have an insight into how my own process has influenced the research. The similarities in the moving experience with my participants allowed me to apply my experiential knowledge in order to place their material into context. My position as the 'other' (Oguntokun, 1998) assisted me in assuming a place of 'not-knowing' in relation to what they were going through as people with learning disabilities.

However, maintaining a 'not-knowing' position was difficult. Having experienced periods of uncertainty, confusion and transition in my own life, I realised that personally I needed certainty and definition, rather than staying with uncertainty and the pure experience. Perhaps this need for definition, could have drawn me towards adopting a stronger interpretative position in relation to the data. Additionally, a sense of confusion might have emerged from my participants' side regarding their transitions, and this urged me to provide explanations and definition in order to make meaning of their experience.

Furthermore, my professional identity as a Counselling Psychologist directed me to understand participants' accounts through my practitioner's lenses. Coming from a practitioner's perspective, my counselling psychology background influenced my stance towards the participants and the relationship that was established during the interview.

Having worked previously with people with learning disabilities, as well as, my knowledge in psychology had equipped me with certain assumptions about my participants. For instance, I realised during the interview process that I had already formed assumptions about how they should have been feeling after the move and the kind of impact this experience would have had on their psychological well-being; something that I would do frequently as a counselling psychologist.

Throughout the research process, I tried to manage everything that could get on the way of my making sense of participants' experience. I tried to develop my awareness as much as I could, making myself aware of my own material and bias and how the latter could direct the research process. I also aimed to gain more self awareness since knowing my self would allow me to be more able to bracket my experiences, as well as, to realise my limitations. This was achieved by keeping a reflexive diary during the research process and by attending personal therapy. A sample of the diary can be found in Appendix 1 (p.307).

14.7. Validity.

According to Elliott, Fischer and Rennie (1999), the value of every scientific method must be evaluated in terms of its ability to provide meaningful answers to questions posed. Usually validity represents the truthfulness of findings (Whittemore, Chase & Mandle, 2001) or their trustworthiness. In qualitative research, validity is connected to the epistemological paradigm adopted and the criteria for trustworthiness are closely linked to the paradigmatic underpinnings of the particular discipline (Morrow, 2005). In any research based on constructivism and social constructionism, like in this study, it is important to acknowledge among other elements like quality and credibility standards, that the nature of the data collected and the analytic strategies are influenced by the researcher's subjectivity (Patton, 2002). A way to manage this subjectivity when doing IPA is the technique of bracketing where the researcher monitors his/her assumptions or preconceptions (Finlay & Gough, 2003; Morrow, 2005). Throughout the research process I tried to be aware of my own material and to manage my subjectivity by constantly

questioning my assumptions about moving home and about the themes emerging from the participants' accounts.

Additionally, this research study followed the guidelines proposed by Lucy Yardley (2008): sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance. The above criteria can be adjusted to the qualitative method used and each particular study.

I tried to establish sensitivity to context by reviewing and being aware of relevant literature around the social and cultural context within which the participants experienced their moving out of the home environment, as well as, the context where the research process took place. Furthermore, I was aware and conscious of the context within which participants' accounts were analysed, that is, how my own assumptions had an impact on the analysis.

In terms of commitment and rigour, commitment refers to engagement with the topic, rigour refers to completeness of data collection and analysis (Yardley, 2008). This criterion was realised by adhering to the following steps: Data were thoroughly and carefully collected. After immersing my self fully in the analysis, I repeatedly made sure that the analysis stayed close to the data, by providing many examples from the transcripts and by revisiting many times the transcripts to check whether the analysis stayed close to participants' accounts. I hope I demonstrated methodological competence through my analytic strategy, described later, as well as, in the analysis itself.

Coherence and transparency refer to the clarity in the description of the research process and the degree to which all aspects of the research process are disclosed (Yardley, 2008). For the purposes of achieving this criterion I provided with full transparency the analytic process. Reflexivity was necessary throughout this study. In order to be able to check on and develop my reflexivity and transparency (Willig, 2001), I kept a paper trail of all data concerned in the development of themes and super-ordinate themes so that all steps and reasoning were transparent and could be followed. This also included a reflexive diary

where I recorded my thoughts, feelings, and ideas during the development of the research, as well as, my impressions from the interviews.

Impact and importance is Yardley's last criterion. I tried to satisfy this by justifying the relevance of this research to counselling psychology. I tried to offer a novel aspect in learning disability research that would provide counselling psychologists with an insight into this population's experience (an experience that is so far unacknowledged). The relevance of this topic to the counselling psychology field is dicussed in the introduction section.

Finally, in order to enhance the validity of this study, a cross reading of the transcripts was performed (Henwood & Pidgeon, 1992). A sample of coded transcripts along with my theme list were looked over by four chartered psychologists with experience in IPA research so as to consider the extend to which the emergent themes and my theme list appeared to be grounded in the text, whether they made sense to them and fitted together. Overall, all researchers agreed with my interpretations and at points where comments were suggested, those were incorporated and the text was altered accordingly. Please see Appendix 2 (p.308) for a sample of their comments.

15. Procedures

15.1. Sampling and Participants

According to IPA principles, a small sample size in a qualitative study ensures that each individual transcript is analysed thoroughly. This procedure is lengthy in nature. In this way premature general claims about the participants are avoided and the study would be able to express more successfully the views and the perceptions of this population (Smith & Osborn, 2003). The number of participants should also be decided in consideration to the size of the data set that would emerge from the interviews and in accordance to the research guidelines as they are published (Turpin et al., 1997).

It should be noted that there is no right answer to the question of sample size in IPA. Smith, Flowers and Larkin (2009) supported that in professional doctorates numbers of interviews (rather than of participants) vary between four and ten. However, the sample size partly depends on the richness of individual cases. A sample size of 14 participants was included in this study. I decided to use more than ten participants based on my previous research experience with people with learning disabilities. In my MSc research on the experience of bereavement for people with learning disabilities (Karavella & Rafalin, 2007), most participants tended to give short answers during the interview, making the data extraction quite difficult. I, therefore, decided to use a larger sample in order to maximize data richness.

My group of participants consisted of fourteen individuals with learning disability, five women and nine men, aged between 25 and over 60+, who had moved from their family home to a care home at some point in their lives and were able to express themselves verbally. Relevant existing literature on moving home and the learning disability population have also used adult participants suggesting perhaps that the experience of moving home can be more common and/or researched in adults with learning disabilities (i.e. Emerson & Hatton, 1994; Howard, 1996; Owen, Hubert & Hollins, 2007). Additionally, 'Valuing People Now: The Delivery Plan 2010-2011' talked about the residential placements of 33,000 adults with learning disabilities. The sample of this study, therefore, consisted of adult participants from 18 years old and over. No further restrictions were made on the sample in terms of marital status, age etc in order to keep the sample as varied as possible.

This study focused on giving voice to people with a learning disability. For this purpose, it was an imperative to focus solely on participants' accounts and not to have others speak for them unless the participants wished to. Therefore, the participants of this study were required to acknowledge having a learning disability, in order to participate in the research. In order to satisfy the accuracy of a learning disability diagnosis without this nullifying participants' accounts, a supplementary criterion was added: that the

participant has/had a direct contact with a learning disability service (as a user) or a specialist in the past. The latter would imply a degree of impairment.

This study focused on participants that had experienced a change of home (from their family home to a care home) at some period in their lives. I estimated that the time elapsed since their move should be at least six months as a minimum transition period. I thought it was of paramount importance that the participants in this study would not be in the middle of moving at the time of the interview, since this experience would place them and their identity in transition. Having being through this transition would, therefore, make them more able to reflect upon the impact of this experience.

This study focused on participants that were able to verbally express themselves. This was solely chosen due to my weakness to assess participants in other non-verbal ways i.e. by using Makaton, Talking Mats or other tools. Although the aim of this study was to give voice to people with LD, it was necessary for me for the purpose of the analysis that the prospective participants were able to respond verbally to interview questions. It is interesting to note that most prospective candidates that showed interest in participating had good verbal skills. Furthermore, one of the reasons that informed my decision to conduct verbal interviews relied on my choice of methodology. In terms of data collection, IPA considers interviews as the best means of accessing a detailed, first-person account of participants' experiences (Smith, Flowers & Larkin, 2009). IPA is also concerned with what a participant thinks or believes about the topic discussed (Smith, Jarman & Osborn, 1999) and through a verbal account one could give a depiction of his/her ideas and beliefs. This is definitely one of the areas that require further elaboration and it will be discussed in the discussion section of this study.

From early on, during the recruitment process, it was evident that the sample of this study was not easily accessible. The recruitment process, therefore, was extensive and included many avenues. In order to recruit participants, an advertising leaflet (Appendix 3, p.309) for individuals with learning disabilities was created. The leaflet was written in a language and a format that people with learning disabilities were able to understand

(O'Hara & Sperlinger, 1997) and it was designed based on books and texts written specifically for people with learning disabilities (Hollins & Sireling, (1989); Hollins & Sireling, (1994); Cathcart, (1994); Hollins, Dowling & Blackman, (1995)). For example, a combination of pictures and text was used to facilitate and enhance understanding.

The advertising leaflet was sent to multiple locations. These included organizations and services for people with learning disabilities, social clubs for this client group, carers' organizations, general counselling services, care homes in and around the London area, housing organisations and umbrella organisations for people with learning disabilities. Most services displayed the leaflet in their premises and others showed it directly to appropriate candidates that may have been interested. Later on, directors or staff members contacted me about any individuals with learning disabilities that were interested in the research.

Attempts were also made to recruit outside London in order to have a more varied sample and to see if the experience of the population living outside London would be at all different. Six participants responded that resided outside London.

15.2. Participants

The participants were fourteen adults with learning disabilities that have moved from their family home to a care home within the last 6 months minimum (please refer to Table 15.2.1. Demographics table, p.83-85). Initially eighteen candidates were interested in participating in the research and were approached. Most of the times, I would get contacted directly by the candidate's keyworker in the care home or by the manager of the organisation that the participant attended. As I was informed the candidates preferred to make the initial contact via their keyworkers/managers prior arranging to participate in the study. Reflecting upon this, I assumed that this might have been a way for the candidates to feel safer about their choice of participating in the study; perhaps by letting someone they trusted to contact me first, since I was a stranger to them, they felt safer with the whole process. I initially explained what the research involved to all

organisations via a telephone conversation and via emailing my proposal and research pack to them. After getting a formal positive reply, I had a telephone contact with the care home managers or staff to arrange a meeting with the potential candidates. After a preliminary discussion, out of the eighteen people that were interested in participating in this study, fifteen (15) candidates matched the research criteria and agreed to participate[5]. Consequently, interviews were arranged and we proceeded straight to the interview. Fifteen candidates participated in the interviews and from those fifteen, one candidate did not complete the interview and withdrew from the process due to an increasing anxiety he felt. Therefore, the number of participants that fully participated in this study was fourteen (14). The participants came from different backgrounds, different age groups and with different personal histories. Ten out of the fourteen participants could read[6]. Participants' biographical details are summarised in the table below. Since it is essential to view participants' accounts in the context of their life story, short summaries have been drawn out for each participant (see Appendix 4, p.310). It is recommended that the summaries are read before the analysis, as a way of contextualising the analysis, and placing the quotes of each participant in the framework of his/her personal life story.

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[5] Out of the three candidates that did not proceed with the interviews (from the eighteen people that initially showed interest), two candidates denied participating after our preliminary discussion because of the recording involved, and one candidate did not reply to my second correspondence to arrange an interview.

[6] For the participants that could not read, all materials were read to them by their keyworker or a member of staff in the care home, prior the interview and were read again to them by the researcher prior establishing consent to continue with the interview.

15.2.1. Demographics Table

Name	Gender	Age	Marital status	Ethnicity	LD Service attended	Educational level attained	Occupation	Change of home	Time elapsed	Previous living circumstances	Reason for moving	No of Home changes	Current living conditions
Mary	F	>60	Single	White British	Yes	School	No	Yes	2 years	1)Family	Inability to be looked after	1	Care home
Angela	F	42	Single	Any other White Background	Yes	College	No	Yes	5 years	1)Family 2) Care home	Inability of parent to take care of her	2	Care home
Philip	M	48	Single	White British	Yes	College	No	Yes	6 years	1)Family 2)Care home 3)Care home	1)inability to be looked after 2) home closed down	2	Care home
Josephine	F	60	Widowed	White British	Yes	College	No	Yes	43 years	1)Family 2)care home 3) husband 4)care home	Inability to be looked after/ death of husband	3	Care home

Lee	M	26	Single	White British	Yes	College	Yes	Yes	6 months	1)Family 2)College	independence	2	Care home
Redhead	M	45	Widowed	White British	Yes	College	No	Yes	11 years	1)Family 2) care home 3)with partner in own flat	abuse	2	Own home
George	M	58	Single	White Irish	Yes	College	No	Yes	3 years	1)Family 2)Care home	Death of parents	2	Care home
Ching Dynasty	M	25	Married	White British	Yes	College	Yes	Yes	4 years	1)Family 2)Family 3)R. home 4) R. home 5) R. home	Parent illness	6	Own home with partner
Alf	M	44	Single	White British	Yes	School until 16	Yes	Yes	20 years	1)Family 2)Residential home	Death of parent/unable carer	4	Own hoe
Tim	M	30s	Single	White British	Yes	College	No	Yes	2 years	1)Family	Parents unable to look after him	1	Care home
William	M	57	Single	White British	Yes	College	No	Yes	4 years	1)Family	Don't know	1	Care home
Charlie	M	52	Single	White British	Yes	College	Yes	Yes	13 years	1)Family	Death of one parent/ financial issues	1	Care home

Jasmine	F	46	Single	White British	Yes	College	Yes	Yes	13 years	1)Family 2)Care home	Independence	2	Care home
Rose	F	43	Single	White British	Yes	School until 16	No	Yes	8 years	1)Family 2)Care home	Independence	2	Own home

15.3. Ethics

The ethical implications of this study were carefully considered in the beginning of the project. A full ethical approval was sought and granted from the Department of Psychology of City University for this research project (see Appendix 5a, p.312). This study also abided to the British Psychological Society Code of Code of Human Research Ethics (2011). The main issues considered were: informed consent, confidentiality and debriefing.

Informed consent for participants with learning disabilities was an issue that required special attention. According to the principles of consent of BPS (1997):

> Research with participants who have impairments that will limit understanding and/or communication such that they are unable to give their real consent requires special safe-guarding procedures.

> Where possible, the real consent of adults with impairments in understanding or communication should be obtained.

> Where real consent cannot be obtained from adults with impairments in understanding or communication, wherever possible the investigator should consult a person well-placed to appreciate the participant's reaction, such as a member of the person's family, and must obtain the disinterested approval of the research from independent advisors (BPS,1997,p. 5).

Informed consent was achieved using a consent form, which was signed by the participants before initiating the interview procedure. A clear account of what the study was about, what to expect within the interview and their rights was outlined at the start, both verbally and in writing, in the information sheet. In order to facilitate the participants' understanding, the information sheet and the consent form (Appendices 6a, p.328; 6b, p.329) were designed specifically for people with learning disabilities according to information sheets and consent forms that were

used by Humlin (2003), Read (2004) and Karavella and Rafalin (2007). As Cable, Lumsdaine and Semple (2003) claimed, in order for individuals to be properly informed, the researcher has to take into account the client's abilities and language.

Participants were given ample time to think about the interview and whether they were interested in participating and eventually gave their written consent. They had the opportunity before our meeting took place to think further about their consent with the help of the staff in the care home or their carers and in the beginning our meeting the issue of their consent was addressed again. This was implemented so that the participants were free from undue pressure to consent (Willner, 2003). The participants could choose to have a carer or a friend with them that would also give consent for the participant with learning disabilities to take part in the research. Another consent form was thus created for carers, staff or friends that would apply to the cases where participants would like someone else to consent with them. None of the participants chose to have another person to sign along with them. The notion of allowing participants to decide on their own, if they wished to, was based on the statement of the Department of Health: "It should never be assumed that people are not able to make their own decisions, simply because they have a learning disability" (2001, p. 1) and on the notion that as a general principle adults that are assumed to have capacity applies "just as much to an individual with learning disabilities as to any other adult" (Panting, 2002, p. 80). All participants were free to withdraw from the study at any point without prejudice.

Overall, process consent (Beaver, Luker & Woods, 1999) was used in this study. During the past years, informed consent has been described as a static procedure and researchers often felt that this static model of consent is inadequate (Usher & Arthur, 1998). In qualitative research it has been argued that informed consent is almost impossible to be achieved due to the changing nature of the data collection (Ramos 1989, Streubert & Carpenter 1995). Researchers, therefore, particularly those using qualitative designs, have proposed the use of process consent. Ramos (1989) offered this alternative notion of informed consent for qualitative research: '... ongoing consensual decision-making, where emerging difficulties are discussed

openly. The respondent is kept informed as to his vulnerability to potential dangers, and the investigator and participant, make research decisions as a team' (Ramos,1989, p. 61). This type of consent is what Munhall (1991) later referred to as 'process consent'. She suggests this encourages mutual participation and mutual affirmation between researcher and participant, and offers an opportunity to actualize a negotiated view. Dyer & Bloch (1987), who hold that informed consent should be viewed as a continuous process, used the therapist and patient within a psychotherapy framework as an example. They claim that within this relationship informed consent occurs not once but repeatedly. According to Beaver, Luker and Woods (1999), process consent 'allows consent to be renegotiated at different stages of the interaction between the researcher and the participant… the concept also has relevance for cross-sectional designs when an experienced researcher needs to be sensitive to the needs of the interviewee in understanding the fluid nature of the interview process. Physical condition or psychological state may alter during the interview process and consent may need to be re-negotiated…' (Beaver, Luker and Woods, 1999,15). Although this approach may constrain the research design in that sample size may be reduced and missing data may ensue from half-finished interviews it has been argued that care takes priority over research (Raudonis, 1992). This notion of prioritising care over research was central to this study. In order to ensure that process consent was appropriately carried out, I followed several steps. Consent for all interviews was discussed with participants prior arranging the interview and on the day of the interview after meeting me. I made sure that participants had access to all the interview material before they made a decision to proceed with the interview by sending the material to the participant's home address or to the participant's keyworker, who had made the initial contact. Furthermore, throughout the interview I monitored closely participants' behaviour and mood and every time I would perceive any signs (i.e. tiredness, boredom, agitation, restlessness etc), I would ask if it was ok to proceed with the questions, if they needed a break or whether they wanted to stop. In case a participant required a break, after the break I sought again consent in order to continue.

Confidentiality was kept throughout this study. The interview recordings, as wells as, all forms and questionnaires were kept in a locked cabinet in the university office. All information provided by the participants has been kept confidential and all identifying information has been removed from the material that has been made public. Transcripts were fully anonymized. The consent forms that had the participants' real names as well as the demographic forms were kept separately from the data. All computer files with identifying details (i.e. interview recordings) were kept under password. All participants chose their own pseudonym that they wanted me to use it instead of their name.

I did not foresee any risk of mental harm to the participants during the process of this study. However, due to the possibility of emotional issues arising during and after the interviews, debriefing was structured in a number of ways. At the end of the interview, all participants were asked how they felt about the process and what they thought about it. This was done to give participants the opportunity to feedback any negative effects the interview might have had on them. Additionally, all participants were provided with a list of services (Appendix 7, p.332) that they could contact, if they wished to, for emotional and psychological support, as well as, for other kind of help. All participants welcomed that information. A final report detailing the findings of this study was sent to participants in order to inform them about the outcomes of this study (Appendix 8, p.338).

In the case of the candidate that withdrew from the interview process due to anxiety, I immediately stopped the interview after the first few minutes when I realised he was uncomfortable. I checked again his desire to do the interview and gave him the option to stop. The participant decided to stop and gave me his consent to notify a member of staff that he did not want to continue further with the interview. All measures were taken to ensure that a member of staff was notified and the candidate was given adequate support. Although the resources list was provided to him, the candidate did not feel that he needed to talk to someone further about his experience.

None of the participants in this study had a visual impairment. However, the following provisions were made, should there had been an individual with vision difficulties. As with all candidates, the participant with visual impairments would have access to all the interview documents prior our initial meeting in order to review them with the help of their key worker or a person close to them. During the meeting, all documents would be read aloud to them before they decide to give their consent. Should they wished to, participants could have another person with them to confirm the accuracy of the documents read, clarify any issues with regards to recording and consent alongside them.

15.4. Semi-structured Interviews

Semi-structured interviews were the main method of data collection in this study. My choice of the interview method was based on relevant literature. Thomas and Woods (2003) stated that many individuals with learning disabilities were still able to have a coherent verbal conversation, even if their learning disability affected a small degree their ability to communicate. Smith, Harre, and Langenhove (1995) highlighted that with semi-structured interviews the participant can be regarded as the expert and is allowed the maximum opportunity to tell his/her story. Additionally, they acknowledged semi-structured interviews as the most useful method when conducting qualitative research, especially IPA, since it provides the researcher with the flexibility to follow the guidelines of the interview schedule, while allowing change and variation for each individual participant.

After the initial explanations regarding the research project, a time and place was arranged for the interview to take place that was convenient for the participants. The interviews were conducted in the participants' care home or in the premises of the umbrella organisation that had made contact on behalf of the participants. Interviews lasted approximately 35-40 minutes each. All participants reported that they enjoyed the interviews and the opportunity to talk. The length of the interviews was relatively short and this was possibly related to the nature of this population. In Karavella and Rafalin (2007), the same observation was made regarding participants' accounts. Participants

answered questions briefly and needed a lot of prompting to express themselves. At points, the statements lacked richness and needed perhaps more elaboration from the participants. Even though, words were scarce, the atmosphere of the interview was particularly emotive. The length of the interviews could have been affected by the limitations of the interview schedule itself. Concepts in the interview material such as identity (who I am) can be very complex and it can be difficult for participants to articulate.

In addition to the interview and for demographic purposes, a Pre-interview Demographic Questionnaire was adjusted from Karavella and Rafalin (2007) a 'Pre-Counselling Bereavement Questionnaire'. I assisted participants in filling in this short questionnaire of biographical details (please see Table of Participants' Biographical Details p.83). The questionnaire asked participants basic demographic information (i.e. age, ethnic origin, education, employment, learning disability service attended etc) and served as a way to elicit very general background information but also to confirm the inclusion criteria for the study.

An Interview Schedule (Appendix 9, p.342) was also developed taking into account previous research (Humlin, 2003; Read, 2004; Karavella & Refalin, 2007), as well as, the guidelines offered by Smith and Osborn (2003): being neutral in order to grasp participants' experience while staying close to the research agenda. Also, a broad range of areas to be discussed was brought up (Smith, Harre & Langenhove, 1999). These were: preliminary questions about identity, background information about change of home, feelings immediately after moving home, change, impact of changing home, change over time, things that help or did not help. These were arranged in this order so that the more sensitive or private topics to be addressed later in the interview after rapport has been established (Smith, Harre & Langenhove, 1999; Willig, 2001; Humlin, 2003).

Questions were developed for each area. Both open-ended and close-ended questions were used. There was a particular effort to minimize the use of 'yes' and 'no' questions, mainly because of the tendency of people with learning disabilities to respond

affirmatively (Sigelman, Budd, Spanhel & Schoenrock, 1981a; Sigelman, Budd, Spanhel & Schoenrock, 1981b; Sigelman et al., 1982). A series of prompts was also used in each of the questions, if they were needed to elicit more information in the interview (Humlin, 2003). The language and the vocabulary of the questions were adjusted to each participant's level of understanding and at times questioning was repetitive and explanatory. Summarizing was used frequently to allow participants to focus and add more detail (Emerson, Hatton, Bromley & Caine, 1998). An effort was made to be as natural as possible, so that the interview resembled a natural conversation, as it is advised by the literature (Smith, Harre & Langenhove, 1999; Goodley, 2000). The questions were not always phrased the same way. As Goodley (2000) suggested, the focus should be on the interviewee and not to the interview protocol. Interview questions aimed to allow the participants to feel comfortable by sharing their experience in their own way. Consequently, the interview changed from one participant to the other, using the interview schedule as a framework.

15.5. Researcher's Experience of Conducting the Interviews

In the beginning of the meeting, introductions were made between all parties. The care home staff usually made introductions first and then left us to continue with the interview schedule after consent was established. I introduced myself to participants and told them a little bit about myself and the reason I was doing this research. At that point, I allowed participants to share information about themselves, should they wish to. Shortly after that, we proceeded to the research material. I gave participants their information pack and read aloud the information sheet and the consent forms. After that, participants had the time to ask questions and when they were happy to give their consent, we continued with the interview schedule.

One of the challenges that I faced in the interview process was that some participants had difficulty in understanding one or two questions of the interview schedule and/or found them hard to respond to. In order to overcome that difficulty, I rephrased the questions using simpler language or broke them down into smaller questions. Participants seemed

to respond to this tactic. In case a participant was still not able to answer, I continued with the interview schedule without pressurizing him. Another challenge that emerged through the interview process was the fact that some participants had difficulty in remembering details about moving home or about themselves, prior the move. During the interview, I allowed participants ample time to answer those questions. Additionally, I repeated those questions at the end of the interview schedule to give participants another opportunity to reply. I also tried to stimulate their memory by asking whether they remembered anything about that period of their life and started building up from that, in order for them to recall that period. For some participants this worked, but on two occasions participants were not able to remember.

Since interviews were quite long for this client group, we took natural breaks during the interview process depending on the needs of each participant. I had informed the participants prior to the interview schedule that they could ask to have a break whenever they needed to. Some participants asked for a break to visit the toilet or have a cup of tea or a glass of water. In one case because it was lunchtime, we took a break so that the participant could have lunch. I also observed carefully for any signs of tiredness, impatience or boredom in participants and, when those were apparent, I suggested a break or enquired whether they wanted to stop the interview process. Participants were usually happy to proceed with the interview and on rare occasions they asked to stop the process. One participant towards the end of the interview asked for a pause in order to have a cigarette outside (because he was not allowed to smoke inside the care home). During those breaks I stopped the recordings and resumed it when participants returned.

Another challenge I encountered during the interviews was that some participants spoke with different accents and at times their speech was unclear to me. Due to the fact that I am not a native English speaker, I often struggled with different English accents. In order to overcome this, I often summarized participants' responses repeating them back to participants so that they could confirm their account. With this action I was trying to ensure that I had understood what participants were saying making sure I was not misinterpreting them.

15.6. Transcription

The interviews were recorded on a tape recorder and transcribed verbatim. The transcript included vocal utterances such as ahh, hmm etc, repetitions and unfinished sentences as well as non-verbal communications where relevant. I aimed to create a text that was a close representation of the interview.

15.7. Analytic Strategy

In IPA analysis the researcher conducts a case by case detailed work on individual transcripts. The analysis of this study evolved through layers of interpretation and included different levels of analysis: from exploring what the participants were describing, to laying connections between different statements within one interview, and finally to revealing certain processes during the thematic analysis of all interviews. This process depicts the hermeneutic circle (Smith, Flowers & Larkin, 2009).

I started by listening the interviews several times and took notes. Then, once transcribed, the transcript was read carefully several times, in order to fully immerse myself in the data. At this stage, the entire transcript was treated as data and I did not put any emphasis on particular excerpts. The aim was to understand the content and complexity of participants' experience and their inner world. As I would read the transcripts, I would also listen to the interviews, in order to keep the feeling of the participants' talking. At this stage, tentative ideas, thoughts and reflections were written on the left hand margin of the transcript regarding interesting and significant passages. These included comments on anything striking such as particular phrases or wordings, manner of speech, emotional reactions etc. The initial themes derived by reading through the marked passages and the comments into the left hand margin were written on the right hand side margin of the transcript (Smith & Osborn, 2003) (see Appendix 10, p.345).

Themes were listed in chronological order separately. I then tried to understand the connections between the themes and I started clustering them. This process was done for each individual transcript separately. During this process the analysis moved from the descriptive level to higher-level interpretation. At each stage the emergent themes were strongly supported and grounded in the data (Smith & Osborn, 2003), and I would go back to the transcript to check that the meaning stays as close as possible to the data (Langdridge & Hagger-Johnson, 2009). A document was constructed for each participant with themes, subthemes, and their corresponding line numbers and quotes (see example in appendix 11, p.346). Following this, the themes from the different transcripts were grouped together, connections between them drawn up, as well as, commonalities and differences between participants were noted. This was an interactive process: I was identifying repeating patterns among cases, but at the same time I kept an eye on new phenomena emerging. Only themes that were strongly supported from the data of all or the majority of the interviews were selected, and a table of super-ordinate themes was constructed (Smith & Osborn, 2003). Super-ordinate themes were reviewed and reorganised so that the final document of super-ordinate themes would capture the essence of participants' experience. Please see Appendix 12 (p.353) for the master document of themes as well as details of each sub-theme.

The outcome of this process was a tentative model, which demonstrated participants' experience of moving home and its links to their identity. A graphic representation of the model can be found in Appendix 13 (p.360). At this stage, a sifting, thinning and refining took place, both on the level of themes and sub-themes, as well as, on the quotes. The less relevant themes and quotes were put aside to maintain coherence and briefness. Within the write up stage, a re-evaluation of theme labels was conducted, as well as, a refinement of the quotes by cutting out what could be dispensed with, for example repeating utterances such as ahhh, ummmm, without compromising the meaning of the quote. At this stage the analysis started to take shape, and final decisions were made as to what would be included in the final draft of the analysis.

16. Chapter Three: Analysis

16.1. Introducing the Analysis

In the analysis, the main themes and the sub themes emerging from participants accounts are presented in detail, supported with illustrative quotes. The name of the participant, the interview number and the line number of the interview are referenced in parenthesis after each quote. When included, missing data from the transcripts is represented with brackets i.e. …, or by (inaudible word) or (inaudible phrase) or (unclear).

Illustrative quotes tend to be short, as most participants tended to give short answers during the interview. Replying in short sentences was a characteristic often observed in all interviews and which was also noticed in my previous research on learning disabilities and bereavement (Karavella & Rafalin, 2007). A possible hypothesis about this phenomenon could rest with the open-ended questions used in the interview schedule (please see Appendix 9 (p.342) and the section on *Semi-structured interviews* in Methodology p.90) and on their level of understanding. According to relevant literature, individuals with learning disabilities are more likely to give limited answers to open-ended questions depending on their level of understanding (O'Hara and Sperlinger, 1997).

With participants using very short sentences, there was significant difficulty in extracting themes from the data and understanding the participants' meaning making process of their experience (for a fuller elaboration on this please see the section in Methodology entitled '*Epistemological Reflexivity'*, p.69).

There were many times when I was preoccupied with the richness of the data and how a theme would be adequately justified and supported (please see the section on *Epistemological Reflexivity* p.69 in Methodology). Therefore I thought of integrating theory into the analysis section, in order to enhance and support the richness of the analysis when that deemed necessary and to assist in the meaning making process. This

was performed in such a way so as to ensure that participants' accounts would not be overshadowed.

Themes are presented in a particular sequence based on how participants would make meaning of their experience of moving home; that is, in the order they would tell their story and understand their experience.

The number of times each theme in each central category appeared was presented in descriptive terms in the analysis and not in percentages (for example, many, most, all participants etc). Krueger (1994) favoured using one's own words as opposed to quantifying data because it is less complex and more understandable.

Participants had the opportunity to choose their own pseudonyms for the interview and these are the ones that accompany their quotes. At times, participants chose to be called by a keyworker's name or a name of a person emotionally close to them i.e. a family member. Three out of the fourteen participants chose to have their own names used in the data. Out of these three participants, one chose to be called by his/her first name and the other two to be called by their middle name. Having the opportunity to choose their own name or even their pseudonym seemed to be important for participants and this could act as a source of empowerment. Perhaps having the choice of how they wanted to be represented gave participants the opportunity to have their voice heard, but also a chance to represent their identity.

16.2. The Analysis

In the process of analyzing these fourteen interviews, a wide variety of themes emerged from the participants. However, due to the specific length of this work only the most representative ones will be discussed in this section. Although each participant's experience was unique, common themes arose during the analysis of data. Five overarching and interconnected themes emerged from the participants' accounts. Each of these was subdivided into a number of sub themes.

- Who I am

This theme discusses in detail participants' identity, in particular their personal and social identity. In this study, participants defined personal identity as how they saw themselves. Participants linked their self concept with their place of origin, their hobbies, pleasurable activities and their emotional state/inner self. Additionally, participants defined their social identity as how others see them. Participants described their appearance, how they come across to other people, their social roles, their group memberships as well as what they do for others around them.

- The move

This theme examines the moving experience for the participants. Participants talked extensively about the reasons for moving to the care home. Most participants felt they had no choice with regards to the move, since it was not entirely their decision. Many participants described that they had to come to terms with moving home and accept that this was going to happen. A sense of lack of control was evident in their accounts. Furthermore, participants discussed how moving home was for them, as well as, their feelings about this process.

- The new home

This theme examines participants' views about their new home. Participants talked extensively about how they felt in their new residence. Many participants talked about adjustment being difficult for them and how they had to settle down and get used to their new surroundings. Moreover, it seems that the presence of people in the care home - residents or staff – have had an impact on participants. Participants also mentioned how they were influenced by people outside the care home - family, friends or the wider community.

- Things changed after I moved

Another major theme in this study involved the change following the move to the care home. Participants in this study noticed changes in their self-concept, in their relationships with others and in their immediate surroundings. However, for some participants things remained the same.

- My self after the move

This theme discusses in detail participants' identity after moving to the care home. Participants talked about their degree of dependence and independence; that is, what they

needed help for and what they were able to do on their own. Furthermore, they discussed about learning new things and their current feelings about the care home. Participants spoke about how this whole process of the move was experienced by them and what meaning they made of it. Moving on from their experience of moving to a care home was frequently described in participants' accounts. In conclusion, participants offered their own advice about moving home after going through this process.

In the discussion section of this study (p.132) there is a pictorial representation of the experience of moving home for people with learning disabilities and its impact on their identity.

17. Who I am

Who I am relates to the construct of identity described by Erik Erikson. Many definitions have been used over the years for the concept of identity. Deaux (1992) defines identity by contrasting it with the concept of self, linking the former to social roles and personal internal and external characteristics. Over the years researchers have argued about the concept of identity and the different aspects of self. One of the debates focused on the distinction between personal and social identity. Reflecting upon the existing literature around this distinction, identity seems to encompass both aspects of the personal and the social self. Sometimes, it is very difficult to distinguish one from the other since both of these aspects are so interwoven. It is, therefore, difficult to view personal identity without one's social history and context since people experience both a personal and a social identity. According to relevant literature (Dudley-Marling, 2004[7]), this also applies to people with learning disabilities.

Several themes emerged from this study that seem to suggest that for most participants, 'who I am' is expressed via both the personal and social dimension. Participants in this study spoke extensively about who they were in a simple and open way. For participants,

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[7] For instance, Dudley-Marling (2004) in his study on the social construction of learning disabilities demonstrated with several examples how the learning disability identity is constructed in the context of social relations.

this question encompassed two dimensions: how they saw themselves and how others saw them.

17.1. How I see myself

All participants spoke about how they saw themselves in their everyday life. This included narratives about where they came from, what they enjoyed doing in their life and how they felt about themselves.

17.1.1. Where I come from

Most participants spoke about where they came from as part of who they were. Some participants talked about their place of origin. This was usually the town or the city they were from or their place of birth. For instance, Angela said:

> *I was born in Bristol (Angela, 2, 88)*

The place of origin was one of the first things Angela said about herself during the interview and it seemed to be of great significance to her, probably because it referred to where her life had started. For Angela, her place of birth could have a strong link to her identity prior moving to London. It seems that participants in this study considered place of origin and locality as being important to their identity/self-concept.

In addition to towns and city names, some participants mentioned their previous home address and the suburb as part of who they were. Some participants even gave their house number. Lee said:

> *We used to live up in Tollgate Lane, Gilligham (Lee, 5, 32)*

Once more it is evident from the participants' narratives that the place of their home was linked to their sense of self. People have a specific relationship with their home environment and it seems that this applies to the learning disability population too.

17.1.2. Things I am good at…things I enjoy doing

As part of the theme 'Who I am', all participants spoke about things they enjoyed doing in their everyday life such as hobbies or routines. All participants spoke about hobbies and activities they did frequently, and how spent their time. Some activities were indoor activities. For instance, Angela and Philip said:

I do needlework (Angela, 2,6)

Listen to music (Philip, 3, 264)

Tim when asked about his hobby, said instantly:

I watch me television and this timer (Tim, 10, 12)

Some participants spoke about doing outdoor activities. Charlie spoke about engaging in a variety of sports:

Um, I play football. I play pool and snooker (Charlie, 12, 18)

Apart from things they enjoyed doing, participants spoke extensively about things they were good at. Some participants spoke about having particular skills related to work or volunteer activities, like Mary did:

I'm, I'm good with children (Mary, 1, 14)

Some participants expressed their efficiency with arts and crafts. Josephine said:

Oh, I'm good at, um, sculpture and things like that. (Josephine, 4, 18)

Overall, it is interesting to note how participants focused on their hobbies and/or the things they liked doing or they were good at as part of who they were, instead of focusing on occupation, which is used to express identity and is central in the identity reconstruction process for people following the onset of disability (Price-Lackey & Cashman, 1996; Ludwig, 1997; Ludwig, 1998; Rebeiro & Allen, 1998; Dickerson, 2000; Unruh, Smith & Scammell, 2000; Laliberte-Rudman, 2002). Perhaps we can reflect upon the possibility that for this population activity-and not occupation- is central to the identity reconstruction and management.

As part of the things they enjoyed doing, some participants spoke about their everyday routines. Philip said:

Um I travel a lot; I travel a lot by train (Philip, 3, 6)

George repeated many times during our conversation:

> *I smoke and I drink tea (George, 7, 226)*

For participants everyday routines seemed to define their schedule, having an almost ritualistic character. According to Fiese, Tomcho, Douglas, Josephs et al. (2002), rituals are symbolic in nature and convey who we are. Taking into consideration participants' accounts, it seems that for people with learning disabilities routines and rituals could be indicative of who they are, as it is for the general population.

17.1.3. How I feel inside

A significant part of who I am was connected to how participants felt inside. Participants expressed openly their feelings about themselves. All participants had a positive view of themselves. This was confirmed in Mary's and Josephine's statement:

> *I feel quite, quite good about myself. (Mary, 1, 36)*
>
> *I feel happy in myself (Josephine, 4, 382)*

Some participants expressed feeling ok in themselves briefly giving away a feeling of satisfaction, such as Angela and Philip:

> *Well, I'm all right. [laughs Angela, (2, 350)*
>
> *All right (Philip, 3, 31)*

Although most participants spoke briefly about their internal state, some participants showed remarkable insight by describing in detail their emotional process, even when this was not a pleasant one for them. For instance, Josephine said about herself:

> *Well, sometimes I can get het up a little bit, you know, and worry about things*
> *(Josephine, 4,40)*

Participants' choice of words to express their internal state was particularly significant. Although the interview process felt very emotional, most participants seemed to use little emotional vocabulary to express how they felt and most of their statements were brief. From the participants' accounts we could make the hypothesis that perhaps people with learning disabilities have difficulties in expressing emotion and in using emotional language to express how they feel.

17.2. How others see me

Another part of 'Who I am' for the participants in this study included 'How others see me'. All participants spoke about how other people would see them in relation to their identity. This entailed participants talking about what they looked like, how they came across to people, their role in society, the groups they belonged to, as well as, what they did for others.

17.2.1. What I look like

Participants spoke extensively about their physical appearance. For most participants, describing what they looked like, was the first thing they said about themselves. Some of them described their physical characteristics such as their height, their hair colour or their eye colour or features that stood out.

For instance, Charlie described himself:

> *white hair, brown eyes, wear glasses (Charlie, 12, 4)*

This was echoed by Ching Dynasty, who spoke confidently about his physical appearance with a sense of pride:

> *Ah, tall, dashing. Ah, lovely blue eyes, dark blond hair (Ching Dynasty, 8, 10)*

In this research study, how participants looked like seemed to be significant in terms of who they were in relation to others. This finding seemed to be congruent with relevant literature on this population. For people with learning disabilities, an essential part of personal identity is personal appearance, and for some communities it is particularly important to pay attention to dress, hair and skin care and personal hygiene (O' Hara, 2003). Furthermore, it was noted that this finding had links with social identity literature connected to the general population. For instance, according to Dion, Berscheid and Walster (1972), a person's physical appearance is the personal characteristic that is most apparent and accessible to others in social interactions. Folk psychology has encouraged the prediction of someone's character and identity by their appearance. Additionally, appearance seems to play a fundamental role in group stereotyping processes (Macrae, Stangor, & Hewstone, 1996). It seems, therefore, that the factor of physical appearance would play a similar role for the participants of this study.

17.2.2. How I come across

Participants also spoke about how they come across as people. Participants talked about themselves by using adjectives that characterized them. Some spoke about their nature or their behavior. For instance, Philip said when asked to describe himself:

Quiet (Philip, 3, 36)

Other participants spoke about their attitude and values in everyday life in relation to other people. This was echoed in Ching Dynasty's statement:

Um, very committed person. Very honest. Very open. Always speaks the truth. Ah, very reliable. Um, very considerable, respectful. Um, strong (Ching Dynasty, 8, 12)

It seems that participants in this study considered their behavior, attitude and values as a reflection of their self that is projected to the outside world.

17.2.3. What is my role

Most participants spoke about their social identity, focusing on the multiple roles they had in their everyday life. Some participants spoke about the different roles they held within their families. This was echoed in Angela's statement when she spoke about her multiple roles in her family:

I'm their daughter (Angela, 2, 142)

I'm his niece (Angela, 2, 148)

Angela emphasized her position in the family implying that she was a priority to her uncle:

Don't forget, I'm the eldest… I mean, I'm his sister's daughter as well (Angela, 2, 150)

Acquiring a social role seemed to be important for participants' self-definition. In Angela's case assuming multiple roles seemed to give her life a meaning. Angela seemed to exist through her family and to live for her family, putting her family in the centre of her life.

17.2.4. Groups I belong to

Participants spoke extensively about their group memberships. Participants identified themselves as being part of a particular group and talked eagerly about their belongingness to it.

For example, this was echoed in Redhead statement about being a football supporter:

> *(I) support the best football team and that is Arsenal (Redhead, 6, 72)*

Their sense of belongingness was also expressed in their speech with the use of the plural 'we' instead of singular 'I'. that assigned them directly to a particular group. For instance, Lee spoke about being part of the group of residents in his care home and the rules they have to adhere to:

> *Yeah, like we have got to take it in turns at night to cook the dinner. We're now allowed to be all in the kitchen at the same time. We've got different times for cooking (Lee, 5.122)*

Some participants spoke about belonging to a particular ethnic group. For instance, Josephine instantly defined herself as:

> *(I am) British (Josephine, 4, 14)*

Other participants spoke about their marital status, such as Philip who said:

> *(I am)Single(Philip, 3,6)*

All participants identified themselves as being part of the learning disability population. This was echoed in Angela's and Josephine's statements:

> *I have learning disabilities (Angela, 2, 182)*

> *I was a backward child (Josephine, 4,68)*

From Josephine's statement it is evident that she perceived herself as having a learning disability from birth. Perhaps this was a statement repeated to her by her family, later on becoming part of her self-concept. Her choice of words was significant showing that she was aware of the stigma attached to her (similar to what participants did in Jahoda et al., 1988, Jahoda & Markova, 2004).

Group membership seemed to be embraced by participants as a way to express their social identity and at times their preferences. Furthermore, belongingness seemed to

assist participants to define themselves via the characteristics shared in the particular group.

17.2.5. What I do for others

During the interviews, participants talked extensively about themselves by mentioning and describing things they would do for other people. A common theme in their accounts was the provision of help to others. For instance, Angela talked about helping her father:

> *I used to help my father in the clinic because my father's a doctor. I used to be a receptionist, help him and do him drinks and see the patients and my, this, 'cos my father's a doctor (Angela, 2, 182)*

Giving help was also echoed in Josephine's statement about herself:

> *Well, I think I'm nice and people say how helpful I am and things like that and how kind I am (Josephine, 4, 28)*

Participants frequently described their attitude towards other people. This was evident in Mary's statement describing herself:

> *(I am) Caring.(Mary, 1, 22)*

The participants of this study, seemed to perceive their social self through the things they did for other people and being helpful seemed to be at the core of their social self. Perhaps being in the service of others would make participants feel that they were needed and that they played a particular role in society. We could also assume that offering their help or services would aid participants' social inclusion and would make them appear more amiable towards others, putting aside the social stigma often attributed to them.

18. The move

A prominent theme in the participants' accounts in this study involved the process of the move. Several subthemes emerged which seem to suggest that for most participants, the move as an experience entailed several parameters that had an impact on their emotional state. Participants talked extensively about the reasons for moving from their family home to a care home, their lack of choice regarding the move, their feelings about the move and how this experience was felt.

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18.1. Why I moved

A very common conversation around moving home in participants' accounts had to do with the reason of moving. Most participants reported that their families were unable to look after them anymore either due to illness, old age, bereavement or other priorities. This was echoed in Angela's statement:

> *My mum couldn't cope with me 'cos she had a lot on her head then and my father, unfortunately he's a sick man now, he's 77, my dad, and my mum can't look after me and my father at the same time, you know (Angela, 2, 158)*

Some participants mentioned that they had to move due to a change in their living circumstances. For instance, William talked about his father losing his job and their consequent move:

> *They said we've got to move out, because there's um, another bloke that has got cars and bikes, has got bicycles on it, so dad brought us out to Wales (Willian, 11,80)*

Philip spoke about having to move due to difficulties in their previous home:

> *They had to close it down unfortunately (Philip, 3, 55)*

It appears from participants' accounts that their reasons for moving were due to life changes or change of family circumstances and not due to their personal choice.

18.2. I had no choice

Within this study most participants felt that they had no choice regarding the moving process. Most participants confirmed that it was not their decision to move from their family home. This decision, was either made by their family or an external service. This was echoed in Redhead's statement:

> *I didn't have… I didn't make the decision. The person from (Name)People Choice did it for me (Redhead, 6, 160)*

It was evident from participants' accounts that having no choice gave them a sense of resignation that was immediately expressed when they talked about their lack of choice. For example, Alf said :

> *mind you, it wasn't my choice to be there, you know, so there wasn't a lot I could*
>
> *do, so… [sighs] (Alf, 9, 114)*

Perhaps this expressed resignation might have assisted participants to come to terms with their move, making the acceptance of the new situation easier, as it is discussed later on the subtheme *I had to just get on with it*.

Additionally, the participants expressed this lack of choice when they talked about how they got informed about the move by their families or their keyworker. This seemed to take the form of an announcement rather than a conversation upon making an informed decision. For instance, Mary said:

> *Ah, I, I think somebody did, did let me know that I was going to move (Mary, 1, 86)*

This was echoed in Josephine's statement as well:

> *Yes, they told me I was going to move into here (Josephine, 4,106)*

From participants' statements we can witness their exclusion from the decision making process regarding the move. Moving seemed to be a forced option for participants, an option they were not prepared for. It is doubtful whether participants were adequately prepared about moving from their family home or were given the time to get used to this idea, since preparation mostly involved an announcement of them having to move elsewhere.

18.2.1. I had no control…

Following their lack of choice, participants talked extensively about experiencing a lack of control regarding their moving. This was demonstrated in their choice of words that expressed their helplessness. Most participants felt that they 'were put' into the care home. For instance, Ching Dynasty said with a sense of disappointment:

> *And then I was chucked into that place (Ching Dynasty, 8, 112)*

This was also echoed in Philip's and Jasmine's accounts:

> *And the service, of course, put me there, you know. I mean, the service user went*
>
> *and put me there (Philip, 3, 130)*
>
> *I was moved here (Jasmine, 13, 70)*

It is difficult to read participants' statements without having a sense of powerlessness and abandonment. Participants seemed to be dependent on the decisions made by other figures of authority. This was echoed in phrases such as 'being moved' or 'put me there', giving an image of an object being moved and not a person.

18.3. How I found moving

During the discussions concerning the move, participants talked frequently about how this experience was felt. Participants' views can be divided into those that struggled and those that felt positively about moving home.

18.3.1. I found it difficult

Many participants in this study admitted that they struggled with the move, such as Angela:

> *Yeah, of course, I found it difficult (Angela, 2, 492)*

This was also echoed in Jasmine's words:

> *(It was) Difficult (Jasmine, 13, 190)*

18.3.2. I felt good about moving

Some participants talked about the move as a positive experience . This was reflected in Josephine's statement:

> *Well, I really enjoyed moving here (Josephine, 4, 214)*

Others described the move as an escape from their previous home. Redhead said:

> *I was relieved to get out of [unclear], relieved to get out, you know (Redhead, 6.346)*

From participants' accounts, it seems that there were mixed reactions regarding the moving process. Some participants focused on the difficulties of the moving process, whereas others on its result. Participants may have viewed the experience of moving as more positive, should they have made comparisons with their previous living arrangements, like in Redhead's case.

18.4. What I felt about moving

Participants in this study spoke extensively about their emotional state during the move. Participants described a range of feelings related to their experience. Emotion was communicated not only via their verbal accounts but also via their non-verbal communication (i.e. facial expression, mood etc) and the atmosphere during the interview.

18.4.1. I was afraid

Many participants reported being scared when they moved out of their family home. For instance, Lee said:

> *(I was a)Bit scared of moving out (Lee, 5.202)*

Some participants attributed their fear to the uncertainty they experienced during the move. This was evident in Josephine's statement, where we can see her drawing a direct link between her negative feelings and fear with the lack of a prior preparation regarding her move:

> *Well, I felt awful. I, I didn't know what was happening (Josephine, 4,120)*

Additionally, Rose connected her fear with being in a novel situation:

> *I think it's when I'm in a new place, like when I moved house, that was scary, because it was a new situation. (Rose, 14, 38)*

It seems that participants' fear was linked to the position of 'not-knowing' and the uncertainty the move brought to them. Although, not-knowing might be a creative state of being since it provides an openness for meaning-making, it can also bring uncertainty and fear about the future. For the participants, the prospect of a new home was paired with fear.

18.4.2. I was stressed

Apart from their fear, participants described feeling anxious about the move. For instance, Angela said:

I found it really stressful (Angela, 2, 138)

Interestingly, some participants attributed their anxiety to different events happening simultaneously with their move. This was echoed in Ching Dynasty's account regarding his mother:

> *At first I thought, ah, okay, is she all right? I was a bit worried for my mum, I was concerned 'cos she's my mum, and I was very scared. I wasn't scared of the move; I was scared, well, my mum had moved [unclear]. I was worried about her, and it brought a lot of stress to me. So I was very stressed out, and very concerned with my mum. [Coughs] (Ching Dynasty, 8, 44)*

We could make a hypothesis here that perhaps it might have been easier for participants to worry about someone else or something else rather than worrying about their move like in Ching Dynasty's case. In psychoanalytic literature, displacement refers to altering the target of an impulse (Freud, 1937; Baumeister, Dale & Sommer, 1998). Perhaps here we could witness an example of displacement as a defence against anxiety in the learning disability population.

18.4.3. I felt I lost something

Most participants described feeling a loss when they moved from their family home. Loss was a very powerful emotion expressed in participants' accounts. Participants seemed to feel almost bereft or in despair during the move. In some cases, emotions were so intense that participants described being in tears. This was depicted in Rose's statement:

> *The day that I moved out of that house, I just stood in the living room and I just cried. I just thought, well, what have I done, you know (Rose, 14, 70)*

For many participants the feeling of loss was connected to their personal belongings. Many participants described having to leave some of their stuff behind or having to choose what to take with them from their family home. This process seemed to be painstaking for them and showed how attached participants were to their belongings. This was echoed in Josephine's words, said with regret:

> *When I moved from the flat, there was all my lovely glass, glassware and glass cabinet and things like that and, ah, chairs and tables and… I had to get rid of them or have them put in store (Josephine, 4, 160)*

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Most participants described missing their previous home. Philip said about his moving:

It wasn't very nice. I missed it very much (Philip, 3, 91)

The way participants recollected and described the loss of their previous home and their belongings seem to resemble the yearning phase of mourning, as defined by Lendrum and Syme (1992). Participants seemed to view the move as a separation from their previous life and from all surroundings that were connected to their identity.

18.4.4. I felt sad

Participants spoke about the sadness they felt when they left their family home. Even though words were scarce, participants communicated their sorrow via their facial expressions and their body language. For some participants words seemed difficult to come out. For instance, Philip said filled with emotion about leaving his home:

(pause) a bit sad really (Philip, 3, 71)

Furthermore, participants expressed their sadness when they came to say goodbye to their existing family or social relationships. For some participants, moving home meant that they would not see some of their friends or their family again. For example, Josephine said:

Well, I felt sad because I was leaving all my friends there behind (Josephine, 4, 148)

It seems that for the participants of this study feelings of sadness kept them in touch with the reality of the loss and the pain of saying goodbye to their family home and relationships.

19. My new home

According to relevant literature, home is a place that is not static and is always changing, often associated with pleasant memories and intimate situations. The concept of home seems to be tied in some way to the notion of identity. Heidegger believed that the place is the locale of being. He thought about place, placeness and rootedness and thought of those people that had lost their rootedness in place (Sarup, 1994). Participants in this study spoke extensively about being in their new home. They referred to the care home as

being a new place for them and discussed how they felt being there. Participants seemed to have both pleasant and unpleasant feelings and talked about a range of experiences. All participants in this study reported their struggling to settle down to the new environment and discussed the impact that relationships with other people had on them, mainly with family, housemates or staff.

19.1. How I felt about my new home

Participants talked extensively about their feelings about their new home, reporting both pleasant and unpleasant feelings.

19.1.1. I felt good

Many participants reported having a positive stance towards their new home expressing feelings of happiness and satisfaction. This was echoed in Redhead's statement:

> *I just felt… I felt really complete and I felt really happy, yeah. (Redhead, 6, 268)*

Moreover, participants talked about whether they liked the space of the care-home. Some participants talked about their impressions of their bedrooms or the care home's common rooms. For instance, Philip said about his bedroom:

> *Not really. It was all right. Very nice room.(Philip, 3, 153)*

Some participants even expressed their enthusiasm about their new home having a sense of ownership at the same time. Rose said:

> *Exciting. I thought, this is my own house, I can put my own mark on it (Rose, 14, 106)*

I can assume that Rose's statement 'I can put my mark on it' expresses a desire for familiarity and attachment towards her new home. According to relevant literature, these processes underwrite how material environments may come to express or symbolise the self by personalizing the home, i.e. through the decor or design (Dixon & Durrheim, 2004). From the participants' accounts, it seems that perhaps their home could be a continuation of their identity and personalizing it could also create an attachment to it.

Additionally, there were the participant's discussions about feeling comfortable in their new home; some even described having a sense of intimacy, even from the very first time they moved there. For example, Ching Dynasty said:

> *[Coughs]. When I first moved in, it was, ah, it was very good. I felt very nice. It felt, it felt like home, almost (Ching Dynasty, 8, 118)*

Ching Dynasty's choice of words 'it felt like home' is particularly interesting. According to Vaske and Corbin, everyday phrases such as feeling 'at home' is a form of a ''psychological investment with a particular setting developed over time'' (2001, p. 17). Perhaps I could see a connection with relevant literature on place identity and the learning disability population.

19.1.2. I didn't like it

Even though many participants mentioned pleasant feelings towards their new residence, there were others that did not like it. For instance, Jasmine expressed intensely her dissatisfaction, demanding to go back to her previous home:

> *I was upset. I want to go home. [Unclear] I want to go back to (name of place). Because I don't want to go [unclear]. [Unclear] the rest of them. [Unclear] (Jasmine, 13, 76)*

A feeling of dislike concerning the care home was echoed in Josephine's statement as well:

> *When I first come to St. Mary's, I thought, oh, it's horrible, I don't like it here (Josephine, 4, 188)*

It seems that by expressing their dislike, participants also expressed their anger towards their move to their new home. Even though it was not explicitly said, we could suggest and explore the possibility of existing links between participants' dislike and the lack of choice in the decision making process about the move.

19.2. I struggled settling down

A common theme in participants' accounts appeared to be their struggle to settle down to their new home. Participants talked extensively about the difficulties they encountered in

the care home and how they felt. Josephine described what happened in her first night in the care home:

> *Well, there was a, a light that kept shining into my bedroom…and I didn't like it 'cos it used to keep me awake all night I, I kept, I kept saying, getting out of bed and asking them in St. Mary's if I could, if they could sort of change my bedroom and they said no And I said, well, I said I can't sleep in here. I says that light keeps irritating me (Josephine, 4, 178-184)*

Participants described settling down as a gradual process. Participants talked about their initial awkwardness until they were able to get used to the new home. Alf said:

> *Ah… I think the first two weeks were a little bit strange but after that I think I got… I started getting into it, you know, its… try to become a little bit more like home (Alf, 9, 112)*

It seems that adjustment in the new home was a step-by-step process that appeared to be difficult for participants.

19.2.1. I had to just get on with it

During the process of settling down to the care home, participants spoke about settling down with a sense of resignation. Many participants stated instantly (and almost abruptly) that they got used to the new home, their everyday activity schedule and other people in the home without attempting any further elaboration. For instance, Charlie said:

> *No at first. But now I've got used to it (Charlie, 12, 167)*

Participants' statements were mostly brief and seemed rather forced, giving the sense that they had to accept their move and get used to the place having no other choice. This was echoed in Josephine's statement:

> *Well, I… When I, when I moved from St. Mary's, I didn't know why they moved me first off until I got used to it and I got used to Barbara (Josephine, 4,124)*

We can notice in this subtheme some connections with the theme *I did not have a choice*. Perhaps we could make the hypothesis that participants resigned themselves to a new home and got on with their life because they felt they had no control over their circumstances.

19.3. Being with Other people affected me

Participants talked extensively about the impact that their relationships with others had on their life in the new home. These others constituted mainly other residents and the staff in the care home, as well as, people outside the organization.

19.3.1. My housemates affected me

Many participants mentioned being affected by their fellow residents in the care home. Living with other people seemed to be difficult for the participants, especially if they did not know them previously. This was confirmed by Redhead's statement talking about his awkwardness:

> *It was (difficult). Being with new people (Redhead, 6, 364)*

Apart from their difficulty to establish relationships with housemates, some participants mentioned that it took some time to familiarise themselves with and being comfortable with other residents. This was echoed in Ching Dynasty's account:

> *It was very hard to get to know the people, and to know them individually.*
> *It took quite a while to get to know them (Ching Dynasty, 8, 94)*

Furthermore, some participants described having conflicts with other residents.   It seemed that arguments, such as the ones that Angela described below, had an impact on participants' attitude towards the care home:

> *Because, ah, people were… Rian used to irritate a lot. He gets a bad*
> *mood with me and I don't like this mood... With me, I can't, I don't like*
> *this mood because he used to be tantrum on me (Angela, 2, 126)… You*
> *understand what I mean? He used to get bad moods and he's flying, of*
> *course, and, and I didn't like that house from the start (Angela, 2, 128)*

19.3.2. Other people affected me

Participants were not only influenced by their fellow residents, but also by the care home staff, their family and people in the community. Participants experienced the involvement of other people as being helpful during their stay in the care home. Some participants found emotional support in their contact with care home staff, like Jasmine:

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And I talk to staff company [unclear] Not crying. I don't cry. I want you to know [unclear] 'Cos I talk to staff (Jasmine, 13, 316)

Some participants found helpful to keep in touch with their family after they moved to the care home. From their accounts, family contact seemed to be particularly helpful to their adjustment to the care home. For instance, Alf said:

I think the first week or so it was… I was… I was still keeping in touch with my mum so… and I didn't particularly move all that far. I think that helped a lot (Alf, 9, 116)

Another significant impact on participants was the attitude of the general community towards the care home. Some participants talked about receiving support from people in the general community. For example, Redhead said about his neighbours:

Well, people say to me, you're always welcome to come. They really are (Redhead, 6,462)

From the participants' accounts it is evident that relationships played a vital role in their adjustment at the new home. Participants were influenced by their fellow residents and the care home staff, but also by their existing relationships prior to the move, as well as, from the input of the general community.

20. Things changed after I moved

Another major theme emerging from the participants' accounts involved the changes occurring after moving to the care home. Participants reported that things changed after they moved to a new environment. In particular, participants talked about seeing changes in themselves, in their relationships with others and in their immediate surroundings (i.e. their home or their neighborhood). However, there were some participants that claimed things remained the same as before.

20.1. I've changed

The participants of this study talked extensively about changes in themselves after they moved. One's self-concept is usually stable across time (Ethier & Deaux, 1994). Across

the life span, however, there are transitions that can have a significant impact on self-definition (Hormuth, 1990; Ruble, 1994). During these transitions, individuals may find it necessary to adapt in some way to the changes. These adaptations may not be temporary; rather, the new situation may elicit fundamental changes in the meaning, importance, or support that a central identity has (Deaux, 1993).

In this study, participants narrated aspects of their personal development after the move. For instance, Mary spoke about becoming more mature after staying in the care home:

> *Well, I mean, I've, I, I, I've grown up while I've been here (Mary, 1, 242)Mentally*
> *(Mary, 1, 246)*

This was echoed in the accounts of Josephine and Lee describing being more self-sufficient in the care home:

> *Yeah, I am more independent now (Josephine, 4, 370)*
>
> *I do more things (Lee, 5.216)*

Additionally, participants described changes in their mood and emotional wellbeing. Ching Dynasty talked about being calmer after the move:

> *In ways, yeah, I'd say my personality changed. I'm kind of more relaxed; I'm kind*
> *of less stressed [?] [unclear]. No more worries, really (Ching Dynasty, 8, 186)*

In addition, Angela said:

> *I get happy. [laughs] (Angela, 2, 336)*

Participants spotted differences in themselves after the move and it seems that they were able to link those with changes in their identity.

20.2. My relationships with others changed

One of the things that changed after the move was their relationships with others. Some participants spoke about losing contact with friends or family. Some described their contact with their loved ones as not being as frequent as it used to be prior the move. This was echoed in Josephine's statement about her friend:

> *Oh, um, we still see… Sylvia don't come up so much as she used to (Josephine, 4,*
> *262)*

Some participants talked about having fixed contact with their loved ones after they moved. From their accounts it came across how much they wished to see their family or friends. Angela and Tim spoke about their contact with their mothers:

> *Well, this is… I want to say I don't see my mum so often. It's the best time. I see her usually, Margarita, at the weekend and I, I'm going tomorrow. I'm going to see her tomorrow (Angela, 2, 332)*
>
> *Some, sometimes I go on a Friday to mom. (Tim, 10, 150)I don't come back for seven [unclear](Tim, 10, 152)*

For Angela and Tim, maintaining contact with their family seemed to bring some stability back into their lives after the move. Maintaining relationships with friends or family after the move seemed to be important for participants' emotional wellbeing, providing perhaps a link (or perhaps a sense of continuity) with their past.

20.3. My surroundings changed

In addition to personal change, participants spoke about changes they noted it their surroundings in the new home. Participants spoke about differences in space between their family home and the care home. For instance, George spoke about what was different in the structure of the care home and his previous home:

> *Bedroom's upstairs. (7.168) The bathroom was upstairs (George, 7.172)*

Some participants talked about their new bedroom in the care home comparing it to the one in their family home. Participants usually commented on the size of their room and its features that stood out for them. For example, Tim said about his new bedroom:

> *My room's different, when I watch the television. (Tim, 10, 158) (It's) Smaller (Tim, 10, 162) Yes, it has a window on the bottom…(Tim, 10, 166)*

Furthermore, participants spoke about noticing differences in their new neighbourhood. Philip spoke about the amenities around the area of the care home and the distance from his college:

> *The shops are around here (3, 182) Yes, a longer route (Philip, 3, 127)*

Again it seems that participants found contextual changes to be significant, since perhaps to an extent those changes shaped their everyday life.

20.4. Nothing changed for me

Even though participants spoke about things that changed after they moved to the care home, in general some participants claimed that nothing changed for them after the move. This was echoed in Josephine's statement:

Um, no, nothing seems different.

It all seems the same to me (Josephine, 4, 294)

George did not recognize any differences between his previous and his current home:

This house is not different, it's the same as the other house (George, 7.158)

Some participants couldn't pinpoint any changes after moving, like Mary:

I don't, can't seem to find any changes (Mary, 1, 240)

We cannot avoid noticing some discrepancies between Josephine's and George's accounts since in other sections of their interviews they have acknowledged changes after moving home. There are many different hypotheses that we could attribute to this phenomenon. Participants' responses might be connected to the questions they were asked. Perhaps the open-ended questions were too general and difficult for participants to process and, therefore, to elaborate upon. Another viewpoint is that perhaps for some participants their everyday life, rhythms and routines remained relatively the same, so for them change was negligible. Another hypothesis would be that after settling down for some time in the new home it might have been difficult for participants to recall the changes they have been through (memory might also be an issue here). Finally, I could also suggest that participants' reaction could be attributed to a defense mechanism protecting them against the anxiety of change and uncertainty. It might have been easier and less threatening for participants to believe that things remained the same; this perhaps made them feel safer and more secure rather than admitting occurring changes .

21. My self after the move

Another major theme emerging from the participants' accounts involves their perception of their self after the move. Participants spoke about their everyday life and how they are handling it: the things they needed help with, the things they managed to do on their own independently and new things they have learned in their new home. Furthermore, participants expressed their current feelings about living in the care home. Additionally, revisiting their life has assisted participants in the meaning making process of their experience of moving home. Participants talked extensively about the sense they had of their moving experience and also offered their own advice to people that are moving home.

21.1. I need help with things

During their interview, many participants discussed needing assistance from others in the care home either staff or residents in order to perform everyday tasks. From participants' accounts, a common area that participants needed help with was food preparation. This was evident from Angela's statement:

> *Sometime I... I do stuff on my own but by help (Angela, 2, 256) But I can't cook on my own. I'm not good in cooking, you know (Angela, 2, 262)*

This was echoed in Lee's statement, as well:

> *Well, they helped me to tell me how long to cook the food for as well*
> *(Lee, 5.110)*

Some participants talked about needing help with shopping, like Philip:

> *Yes, shopping, food shopping (Philip, 3, 140)*

It seems that by identifying the areas they needed help with, participants may have come more in touch with their limitations and with the areas they needed to develop more. Perhaps this might have enhanced participants' ability to grow.

21.2. I am doing things on my own

Another subtheme emerging from participants' narratives was related to their degree of independence. Many participants described doing things on their own, like Mary:

(I am) Doing things on my own (Mary, 1, 172)

Some participants spoke about looking after themselves, being self-sufficient. For instance, Redhead stated:

I do everything for myself (Redhead, 6, 286)

Some participants spoke about assuming responsibilities and taking care of every day chores in their new home. This was echoed in Ching Dynasty's account:

So I'm going through the process, sort of doing that now. So a lot of, a lot of things has happened since that… you know, recently. I moved into my new place now. I try and sort out bills. You know, like… So far, I've got electric run in…(Ching Dynasty, 8, 152)

Many participants talked about being more independent in their current home. This was evident in Lee's account:

Well, we've got… well, I've got more, uh, freedom here as well (Lee, 5.192)

Participants' narratives about doing things on their own expressed changes in their identity after moving to the care home. Participants described having more independence than before and consequently were allowed to acquire more responsibilities. Perhaps we could view this as a transition to adulthood emerging from the transition to the new home.

21.3. I am learning new things

During their interview, participants talked extensively about new things they have learned in the care home. Many participants said that they were taught by the care home staff how to cook. This was evident in Angela's account:

Yeah. Martin showed me how to do like breakfast and… (Angela, 2, 262)

Some participants discussed how being in their new home has given them insight into housekeeping. This was echoed in Ching Dynasty's statement about home safety:

I learned a lot from moving about, from Crescent Road to where I am now. So at Crescent Road seems, we were covered in a lot of gas [?] and it dripped and stuff like that [?]. I didn't know anything about that, you see. And I did [unclear] for that [unclear]. You know, and things like that, really. I learned… (Ching Dynasty, 8, 166)

Additionally, another thing that participants learned in the new home was to relate to other people. This was expressed in Mary's words:

Well, ah, how to get on with people (Mary, 1, 164)

Moving to the care home seemed to have aided participants in terms of learning new skills. We can only estimate the links of this learning with participants' personal development and the immediate effect on their identity.

21.4. How I am feeling now

Another subtheme emerging from participants' narratives involved their current emotional state after the move. Participants talked extensively about having a range of feelings with regards to their new home, themselves and their relationships.

21.4.1. I have mixed feelings

From the participants accounts, it became evident that participants often had mixed and ambivalent feelings about their new home. This was often depicted by discrepancies observed in participants' statements within the interview. For instance, Philip said about his new home:

Um, it's a bit strange really (Philip, 3, 99) but also added later on *I like the place. (Philip, 3, 119)*

Additionally, this was echoed in Angela's account:

I get tied a lot here (Angela, 2, 138) And I get frustrated with the house, as you know (Angela, 2, 144) and later on said

I'm happy here because I like to sit in the house, do my washing, do my hoovering, do my bit of cleaning and, [laughs], you know... [laughs] (Angela, 2, 252)

21.4.2. I miss…

A prominent subtheme in the participants' accounts was the feeling of loss. Participants described how terribly they missed their loved ones. Angela spoke in several segments of her interview about missing her family:

> *Yeah, I miss my nieces as well as… It's, it's not that I'm living in England and then she lives in America and it's really, really… It's not that… I miss them. (Angela, 2, 48)*

> *and I miss my mum as well, you know.I does miss… Um, I miss her a lot all the time, you know (Angela, 2, 76-78)*

> *Yeah. But there's one gap that's really empty (Redhead, 6.504) My Suzy (Redhead, 6.506)*

21.4.3. I feel lonely

Feelings of loneliness were described several times in participants' accounts after they moved to the care home. William said:

> *Well, it's tough [unclear] I decided. Sometimes you can get lonely, and you can think about it. It can get lonely to think about it, can't you?(William, 11, 154)*

Redhead spoke about his loneliness even though he had the support of a helper:

> *Well, when I'm at home I feel lonely. Even though I've got Susan with me, I feel lonely (Redhead, 6,60)*

21.4.4. I feel anxious

Some participants often talked about feeling anxious after moving to the care home. This anxiety seemed to be related to their loved ones. This was evident in Angela's words about being away from her mother:

> *But she gets tired, you know. She's not young like, you know (Angela, 2, 90)*

Later on in the interview she realized:

> *Yeah, of course, I worry about my mother, you know (Angela, 2, 166)*

Additionally, participants' anxiety seemed to be related to everyday life at the new home. For instance, Ching Dynasty discussed his feelings with regards to changes and interior design at his new residence:

Yeah, yeah, it's, it's very stressful. It is [rattle] like that, because I… We'd just [?]

had a carpet made (Ching Dynasty, 8, 158)

Participants unraveled a range of feelings after moving to the care home. It is remarkable how aware participants were of their feelings and how transparent they were in communicating how they experience life in their new home. By reading their accounts I did not get a sense that their learning disability got in the way of having insight to their emotional state. This made me reflect upon the similarities participants share with the general population in terms of their emotional state after moving to their new home.

21.5. How I have made sense of it all

During the interview process, participants attempted to make meaning out of their experience of moving home by reviewing what happened during this process. Many participants spoke about how this whole process of moving was for them and what it meant to them. Rose shared how her own journey has been:

I think it's when I'm in a new place, like when I moved house, that was scary, because

it was a new situation. I knew I would have to move from my three bedroom to a two

bedroom house. And I wasn't using the upstairs, because we were sort of renting the

upstairs, and I wasn't usually upstairs in my old house. So I thought, well, it's not

really [unclear] before I made that decision. But looking back on it now, I think it

was the best decision that I've made (Rose, 14, 38)

From Rose's account, we can perhaps get a glimpse of how participants understood their whole experience of moving home: going from fear and uncertainty to a sense of relief.

For some participants moving to the care home was a process that slowly unfolded bit by bit. This was echoed in Alf's statement:

Um… Well, yeah, I mean, I [unclear] try to find… get everything right, at the time but

you tend to learn as you go along.(Alf, 9, 222)

By reflecting upon Alf's account, perhaps we could suggest that the experience of moving home for participants could take the form of a developmental process, in which

timing is important for things to flourish, even though one tries to do everything right at each step.

21.5.1. I have moved on

As participants described how they made sense of their experience of moving home, many participants talked extensively about moving on from this experience, coming to terms with it and embracing their new reality. Some participants revisited their decision to move home. For example, Rose approached her decision to move in terms of endings and new beginnings:

> *Well, it was mixed emotions, you know. Wondering if I'd done the right thing, but knowing, I thought that at the end of the day, it would be the right decision for me. I mean, other people might think it different, but for me, I mean, yes, I was sad that I was leaving, but I just felt that that part of my life had closed, that door was shut, and another door had opened. Because there's that fine line and it's sort of, it's like a misty line. You're going through this mist everywhere, going through the mist and coming out the other end (Rose, 14, 76-78)*

Rose described beautifully her moving on process beginning from her ambivalence about her decision. It seems that for Rose going through a process of saying goodbye was necessary in order to proceed to a new start. Even though this process seems to resemble a grey area, perhaps it was crucial for participants to go through it in order achieve their moving on.

As part of moving on, some participants spoke about aspects of this transition that they had not thought about during their experience. Participants portrayed what they would have done it differently if they were going to move again. This was echoed in Alf's narrative:

> *Um… Well, I think I got, ah… I think you always, like, remember… try and remember the good things. Ah… try and remember what sort of, ah, kind of things you like at a place. Ah… some of the things you don't like, I mean, if I was to move again, I would, like, maybe try… try and look around for a bit of, like, beauty. Ah… there's other things… well, that's… that's a good bit, you know, ah… where I would like to*

move into, um… I mean, at the moment, the place I'm in now hasn't got a garden.
Where I was… where I was before, I was in… it was in the countryside, so… maybe,
if I do move again, it's to a bit more… well, I'd like to have a garden because I
want… because when I was living where I was before, I always used to live in town,
bit more to, ah… more busses, more… a bit more…(Alf, 9, 186)

Following Alf's account, we can witness Alf focusing on the positive events in order to cope and be able to move on after the experience of changing environment. It seems that moving on from this experience assisted him in having a new perspective on things and in realising his choices in future decisions. Perhaps we could perceive participants' experience of moving to the care home as an opportunity for personal growth; a chance for them to get more experience in life and in decision-making.

21.6. What I would advise about moving home

Another subtheme that emerged from the participants' accounts involved giving advice about moving home. All participants offered their advice on what to do when moving home. Ching Dynasty was particularly explicit and insisted on the importance of being prepared in advance:

I'd say, make sure you have loads of boxes. (Ching Dynasty, 8, 284)

And lots of black [?] bags, and I always… You know, if you're moving into that lot,
like a location, do your research first. You know, do research on like… You know, do
your research about moving. Like rent places, Councils, you know, buying or
whatever. You know what I mean? Or rent houses, or whatever. Do your research
first about before you move (Ching Dynasty, 8, 286)

And then when you've decided what you want [coughs], make sure you've got enough
money to actually… to do it. Make sure you've got enough money to pay your bills
like your gas, electric, your water. Your Council [unclear] tax… you know what I
mean? And your rent. So make sure you've got enough money for that. Also, you've
got to make sure you've got enough money if you're paying off and stuff like that. If
there's already furniture, that's a big plus, I mean a big plus. But then you've got…
And then you got to make sure you got money for people to move your stuff, and you
get mad [?] with that. So you got to do a lot, a lot, a lot of research, a lot, a lot, a lot

of… yeah, a lot of, like, just [coughs] do one step at a time. Don't just like, I would say, oh, I'm going to move, 'cos it'll be a nightmare. Because you've got to do it. You've got to prepare for it [rattle] first (Ching Dynasty, 8, 288)

And research it. And then get rid of it. Yeah, write all it down (Ching Dynasty, 8, 290)

The issue of preparation also echoed in Alf's statement, who seemed to adopt a more relaxed attitude:

Um… um… well, I don't know, I would tell them to… take your time, consider what you need to do, you need to… you need to say, you know what I mean… make sure you've got everything sorted out before you actually move. I mean, ah… [sighs](Alf, 9, 228).You know, it's…   It depends how organised they are at the time, you know?(Alf, 9, 230)

It seems that for participants in this study, planning ahead prior to moving home was very significant for them, perhaps viewing it as part of the process to have a better adjustment in their new home.

22. Chapter Four: Discussion

23. Discussing the Analysis

In this research project I have encountered a paradox that can be observed in our western society. Although governments vote for laws and documents for the learning disability population that serve their rights and their so-called independence, people with learning disabilities are still treated as dependent and disabled. When strategies fail, the blame is mostly put on the health care system and its inadequacy. We are voting for a more flexible approach to health care in order to serve more needs but instead the services and their systems remain rigid. We, therefore, have to ask ourselves several questions. How feasible is it for change to happen in our society? That is, for this population to have equal rights and independence despite their difficulties? What is the time frame needed? Do we want to change this existing situation? Or perhaps transitions are difficult for everyone?

This section aims to discuss the findings of the analysis in more detail making connections to relevant literature on identity, moving home and learning disability. The section starts with a summary of the findings and then continues with discussing the major themes of the analysis with relevant literature. It, then, goes on with the clinical implications of the research findings making recommendations for practitioners, care home staff and services. The following piece elaborates on the implications for practice in the area of Counselling Psychology. In an attempt to further evaluate this study this section concludes by discussing the limitations of the research, making suggestions for future research, as well as, with the researcher's final reflections.

24. Summary of the Analysis

From the participants' accounts we can definitely observe their experience of moving home unraveling in front of our eyes. Even though each participant carried with him/her their own personal story, there were similarities in the way participants described their experiences.

Following all these stories closely, we are gradually becoming aware of the participants' experience of moving; an experience that brings forward an account of who they are.

Participants focused on two separate dimensions, in particular their personal and social identity. They defined personal identity as how they saw themselves, but there has been a variation in how they presented their self-concept. Some defined themselves via their place of origin, their hobbies, pleasurable activities and their character. On the other hand, participants defined their social identity as how others perceived them. Participants described their appearance, how they came across to other people, their social roles, their group memberships, as well as, what they did for others around them.

Another segment of their story was the moving experience for the participants. Participants talked extensively about the reasons for moving to the care home. Most participants felt they had no choice regarding the move since it was not entirely their decision. Many participants described that they had no option than to accept this event taking place. A sense of lack of control was evident in their accounts.

As their experience unfolded, participants acknowledged the new home as their destination. Participants talked extensively about how they felt in their new residence. Many participants talked about adjustment being difficult for them and how they had to settle down and get used to their new surroundings. Moreover, it seems that the presence of people in the care home – other residents or staff - have had an impact on participants, but also people outside the care home like family, friends or the wider community has influenced the experience of their transition.

Through discussions about the new home, another component of this model emerged: the fact that things changed after participants moved to the care home. Participants noticed changes in their self-concept, in their relationships with others and in their immediate surroundings. However, some of the participants felt that things remained the same in their lives.

Following a period of transition, participants started to talk about the impact the experience of the move had on who they were. One's self after the move, therefore, was another component that emerged through the participants' personal journeys.

Participants talked about their degree of dependence and independence, that is, things they needed help with and things they could do by themselves. Furthermore, they discussed their experience of learning new things and their current feelings about the care home. Participants spoke about what this whole process of the move was like for them and what meaning they made of it. Moving on from their experience of moving to a care home was frequently described in the participants' accounts. In conclusion, participants offered their own advice with regard to moving home after going through this process.

Reflecting on all these themes emerging from the experience of changing home for people with learning disabilities, I will try to formulate this process on a more abstract level. I start with the hypothesis that 'Who I am' (the self) is the base where all experiences took place for participants. 'Who I am' is a fluid area that encompasses both personal and social identities. It is within this area of 'Who I am' where all events unfold and evolve and the individual makes meaning of his/her experience of these events. At a specific point in time moving home appears to be a potential event, which brings changes in the base since a series of events follows: the actual moving, entering the new home and life in the new home. Who I am, therefore, processes those events and evolves along with those events. A change in 'Who I am' emerges from a change in life circumstances. 'Who I am', therefore, undergoes a gradual transformation while trying to make meaning of the new circumstances. The individual becomes aware of the transformation after living in the new home, the latter becoming his/her 'here and now' reality and the self before the move merges with the self after the move.

It is important to conclude that the process of moving home for individuals with a learning disability and its impact on identity is more than just a timeline of events; it is a fluid process where all parts interact with each other and then are amalgamated into identity.

25. A Conceptual Model about the Experience of Moving Home for People with Learning Disabilities

Reflecting further upon the analysis, we can gradually identify an interrelation between the emergent themes and evaluate their contribution to our understanding about the impact of moving home on the identity of people with learning disabilities.

The following diagram is a pictorial demonstration of the relationship between the emergent themes. As it becomes evident, all themes are interconnected in the sense that the one appears to influence the other creating the overall complex experience of moving home and illuminating us further upon its impact on participants' identity.
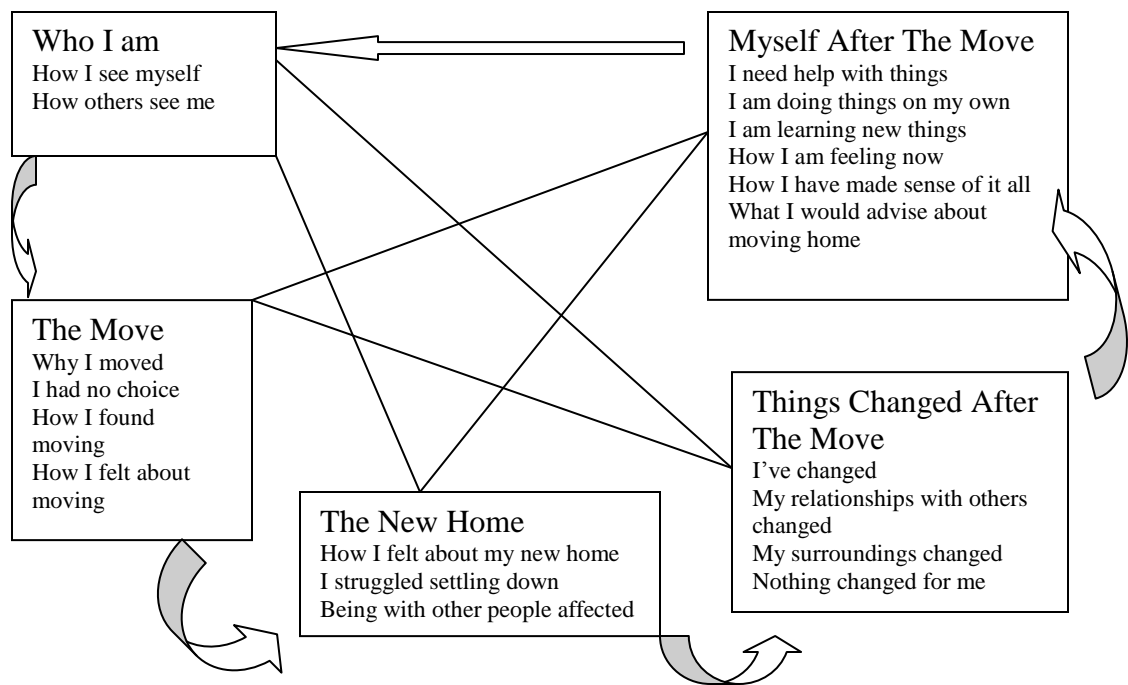
As it is apparent, the relationship between the themes is cyclical on one level. This involves both the dimension of time - that is the chronological order of events and processes taking place (externally or internally to the self) - as well as, the temporal evolvement of participants' identity. For example, 'Who I Am' is the starting point (as well as the ending point) of the experience and, following that, all events unfold. This theme is directly related in that way with 'The Move', which in turn is followed by the theme 'The New Home'. In their turn, these themes/events trigger the thematic entity entitled 'Things Changed After the Move', which in turn results in 'Myself After the

Move', which influences in the end the 'Who I am'. Following the process of the experience of moving home, we can witness its impact on the existing (initial) identity (the 'Who I Am') through 'Myself After the Move', which adds to our understanding of the overall phenomenon. 'Who I Am' and 'Myself After the Move' add to each other and give us a fuller picture of participants' identity following their experience of transition.

On a second level, we can witness other interconnections between all themes. For instance, 'Things Changed after the Move' influences directly 'Who I Am' since participants acknowledged that the first thing that changed was themselves, both on a personal and a social identity level. Additionally, we can observe how 'The Move' has a direct impact on 'Things Changed after the Move'. The reason for moving, the presence or absence of choice when moving home and the overall experience of the move seem to have an effect on the changes participants experienced in themselves, in relation to others and in their immediate environment. Similarly, 'The Move' influences 'Myself After the Move', affecting the participants' feelings about themselves, as well as, their understanding of this experience.

Another apparent connection is the connection between 'The New Home' and 'Myself After the Move'. Participants' feelings about their new home, their struggles to settle down and the presence of other people in their lives lead participants' to the development of their identity . Participants are able to reflect upon their experience of being in their new home and realise their progress on a personal level and regarding their needs. Furthermore, 'Who I am' is connected to 'The New Home' as participants' identity has an impact on their attitude towards their new home; participants' personal and social identity informs participants' feelings and experience about their adjustment to a new environment, as well as, their contact with other people.

The above conceptual model constitutes a response to the research question of this study: 'What is the impact of moving home on the identity of people with learning disabilities?' (That is, how the change from a family home to a care home can influence the identity of a person with learning disabilities).

According to this model, it seems that the experience of moving home adds to the existing identity of the individual with learning disabilities. It seems that through transition and change the person with learning disabilities manages to grow further by realising his/her needs and his/her limitations. Participants in this study acknowledged their strengths and at the same time they identified areas for personal development and areas they needed assistance. This became apparent in the interviews as participants referred to their need of help in their new home since most of them had to assume responsibilities they did not have in that extent before i.e. cooking or cleaning their room. Apart from identifying the instances they needed assistance, participants acknowledged that this process has led them to learn new things. Some participants spoke about acquiring new skills or learning new ways of doing things because moving home exposed them in new circumstances and new demands.

Another impact the move had on participants involved their degree of independence. Participants acknowledged that in their new home they started doing several things on their own without help. For most participants being independent meant that they were able to look after themselves and in some instances their home. Some participants felt they had generally more freedom.

Additionally, moving home seems to have given participants the opportunity to reflect upon the experience of moving and growing from it. Participants' meaning making becomes evident through their advice to others about moving.

Furthermore, the conceptual model gives us valuable information on the following points that constituted the aims of this study:

- The feelings and emotions associated with moving home
- The experience of change from family home to a care home
- Moving home from a personal perspective
- Changes in participants' self-concept after the change of home
- Social identity after moving home

- Coping mechanisms or personal support mechanisms emerging through this experience.

Through the analysis and the conceptual model we can witness that participants' emotions were present in all themes. Moving home brought a variety of intense emotions to participants. Most participants felt loss, sadness, fear and anxiety when they moved from their family home. There were also some that felt relief when they left. Emotions concerning their new home also varied. Some participants felt happy and excited about this change, whereas others struggled settling down, feeling upset and angry. Reflecting upon their experience, participants reported having mixed feelings; many felt lonely missing their previous home, some felt awkward and others anxious.

The conceptual model makes clear that participants considered the actual moving from the family home central to their experience. The reason most participants had to move was the inability of their family to look after them. This is important to highlight because it shows that it was not participants' choice initially to move and that in most cases others made that decision for them. Most participants did not have the time to prepare for the move, usually due to a sudden change of circumstances in their family. This seemed to have an immediate effect on participants' internal world and on their attitude towards their new home. Most participants struggled settling down in their new home encountering various difficulties. Many gave a sense of resignation - that there was nothing they could do about it and had to get used to the new home.

The conceptual model gives insight about changes in participants' identity, as explained previously. Most participants acknowledged a change in themselves that was expressed as a sense of personal growth and an improvement in their mood and wellbeing. Additionally, participants noted changes related to their social identity. They felt their relationships with their families and friends (prior the move) changed since in most occasions contact became less frequent. For most participants living amongst others in the care home proved to be challenging, since they found socialising with other people difficult.

Finally, the conceptual model did not manage to address fully the coping mechanisms or the personal support mechanisms. However, participants refered to the impact of being with other people in the care home and some of them identified other people's involvement as being helpful. Participants seemed to find emotional support from the care home staff. Other significant factors that participants identified as being helpful were family contact and a positive attitude from the outside community that made participants feel welcomed and accepted.

26. The meaning of the Analysis and how it relates to theory

Reflecting upon the participants' accounts and the model that emerged through the analysis, there were several links that could be made with the wider literature on identity, place, choice and adjustment. The small number of participants in this study inevitably means that generalisations cannot be made; rather the following section seeks to explore whether the findings in this study support, contradict, or add to the available literature. A discussion of the findings of this study follows below in relation to relevant literature as well as relevant observations.

27. Identity: *Who I am*

The participants' identity emerged as a major theme of discussion in this study. Participants spoke extensively about who they were. They described both their personal (how I see myself) and social identity (how others see me).

27.1. Personal Identity in People with Learning Disabilities

27.1.1. Place Identity

According to researchers, place acts as a reference to past selves and actions and for some people maintaining a link with a place provides a sense of continuity to their identity (Czikszentmihalyi & Rochberg-Halton, 1981; Graumann, 1983; Korpela, 1989; Giuliani, 1991; Lalli, 1992; Twigger-Ross & Uzzell, 1996). All participants, while describing themselves, referred to their place of origin and the address of their previous home. This

gives some support to the validity of place and its significance to identity and suggests that this could also apply to people with learning disabilities.

Another principle of the place identity theory is the desire to maintain personal distinctiveness or uniqueness. Past research into settlement identity (Feldman, 1990) and community identity (Hummon, 1990) focused on the perceived distinctiveness associated with being a 'city', 'town' or 'country' person. Twigger-Ross and Uzzell (1996) support that people use place identifications in order to distinguish themselves from others. People have a specific relationship with their home environment, which is clearly distinct from any other type of relationship. From the participants' accounts in this study, it becomes evident that all participants considered their home environment significant for them. Participants did not mention being 'city' or 'town' people, but they did comment on their ethnic origin or descent. The latter could be observed in the non-learning disabled population as well. Similarly, the fact that participants in this study did not make distinctions in terms of being 'city', 'town' or 'country' people does give weight to the suggestion that this distinction is less common in the learning disability population.

27.1.2. Hobbies and Everyday Activities

Forrester-Jones et al (2002) in their study about the quality of life of people with learning disabilities and mental health problems living in a community setting found that the most preferred activities were outings, education and work, relaxation and leisure. Andersson, Pettersson and Sidenvall (2007) reported that frequent activities among residents into a care home for older people were: listening to the radio, watching television, reading newspapers and listening to music. There were some similarities between the aforementioned studies and what the participants of this study reported in terms of their everyday activities such as listening to music, watching television and travelling. Participants tended to describe their hobbies and everyday routines as their preferred activities linking them to their identity.

It is interesting to note how participants focused on their hobbies and/or the things they liked doing or they were good at as part of who they were instead of focusing on occupation, which is used to express identity and is central in the identity reconstruction

process in people following the onset of disability (Price-Lackey & Cashman, 1996; Ludwig, 1997; Ludwig, 1998; Rebeiro & Allen, 1998; Dickerson, 2000; Unruh, Smith & Scammell, 2000; Laliberte-Rudman, 2002). Perhaps we can reflect upon the possibility that for this population it is activity-and not occupation- that is central to the identity reconstruction and management. This finding is consistent with psychological and sociological theories on activity and identity management (Kaufman, 1986; Giddens, 1991; Markus & Herzog, 1991; Rose, 1999; Laliberte-Rudman, 2002).

Furthermore, the participants of this study seemed to consider everyday activities and routines as part of their identity - everyday routines seemed to define their schedule. It is interesting to observe that daily routines seemed to have an almost ritualistic character. According to Fiese, Tomcho, Douglas, Josephs et al. (2002), rituals are symbolic in nature and convey who we are. Taking into consideration the participants' accounts, it seems, therefore, that for people with learning disabilities routines and rituals could be indicative of who they are as it is for the general population.

27.2. Social Identity: How others see me

27.2.1. External Appearance

In this research study, participants' appearance seemed to be a significant factor for their sense of self in relation to others. This finding seemed to be congruent with relevant literature on this population. For people with learning disabilities, an essential part of personal identity is personal appearance, and for some communities it is particularly important to pay attention to dress, hair and skin care and personal hygiene (O' Hara, 2003).

Furthermore, it was noted that this finding had links with social identity literature connected to the general population. For instance, according to Dion, Berscheid and Walster (1972), a person's physical appearance is the personal characteristic that is most apparent and accessible to others in social interactions. Folk psychology has encouraged the prediction of someone's character and identity by their appearance. Additionally,

appearance seems to play a fundamental role in group stereotyping related to identity (Macrae, Stangor, & Hewstone, 1996). It seems, therefore, that social identity theories could also be applicable to the learning disability population.

27.2.2. Social Roles

The participants in this study described having a variety of social roles. For instance, they spoke about their family roles, their religion etc. Another remarkable point demonstrating participants' tendency to assume a variety of social roles was the fact that most participants (eleven out of fourteen) chose a pseudonym as a way to represent themselves in the data. Participants' choice of a pseudonym could be interpreted as a way of them taking on another social role, showing us that one's identity could emerge through many processes. All the above, seem to be in accordance with theories on social identity, especially regarding the multiplicity of identity. As Mead stated: 'We divide ourselves up in all sorts of different selves with reference to our acquaintances' (1934/1962, p.142). Listening to participants talking about their different roles, we can witness the multiplicity and complexity of their identities. Investigators have suggested that multiplicity and complexity in one's identity are psychologically desirable and can act as a buffer against stress (Deaux, 1992). Perhaps this theory could apply to the population of this study; having a variety of different social roles to play could assist participants in handling the stress experienced in any single role (Thoits, 1983). Moreover, witnessing the complexity of the participants' identities, gave me also the opportunity to realise how full and intricate their lives are (against a general perception that tends to assume the opposite about this population).

27.2.3. Group Membership

The participants in this study talked extensively about their group memberships. Some of these groups involved ethnicity, a certain sport or group hobby. Some participants even spoke about belonging to the group of residents in the care home. For the participants moving to a new home usually entailed merging into the new group and formulating relationships. It seems that having a sense of belongingness was vital for the participants'

adjustment to the new environment. Participants seemed to perceive their group memberships as positive. Making connections with literature on identity and group membership, we can observe some links between participants' accounts and the Social Identity Theory (Brown, 2000). It is evident that the participants' in this study expressed their social identity via their group belongingness, meaning that the social identity theory could be applicable to the learning disability population.

27.2.4. Learning Disability Identity

People with learning disabilities in the UK might be expected to experience a negative social identity, since they frequently face negative evaluations from others and negative attitudes (Finlay & Lyons, 1998). We could, therefore, admit that there is often a stigma attached to the learning disability population (Jahoda et al., 1988, Jahoda & Markova, 2004). Researchers have noticed that some people with learning difficulties deny their label because they experience it it as a traumatic fact (Koegel & Edgerton, 1982; Hollins & Evered, 1990; Szivos & Griffiths, 1990; Sinason, 1992; Harris, 1995). In a study on social identity and people with learning disabilities, participants did not often make use of the term 'learning difficulties' when describing themselves or interpreting their experiences (Finlay & Lyons, 1998).

Reflecting on the aforementioned literature, there are some links observed between the observations above and the findings of this study. Participants in this study acknowledged having a learning disability at the start of the interview and identified themselves as being part of the learning disability population. Some spoke about it more openly and spontaneously than others, but none of them denied this label. However, the participants in this study did not repeat often the term 'learning disability' when refering to themselves and prefered to talk about other aspects of their identities. Attempting to make meaning of this finding, we are quoting the observations of Fine and Asch (1988). Both researchers concluded that there is the assumption by scholars in psychology that disability must be central to the self-concept of people with disabilities. They emphasised that people with disabilities have so many other attributes and social identities that researchers should not assume that the disabled identity is central to their self concept. This observation seems to be congruent with the multiplicity of social roles that we

previously encountered in the section *Social Roles*. Indeed, people with learning difficulties have rich lives in many different aspects, such as in immediate relationships, achievements and other experiences.

This distinction between personal and social identity echoes the discussion in Deaux (1992), where both these concepts are brought together and are finally integrated into the self. It seems that this integration of personal and social identity also applies to people with learning disabilities bearing many similarities to the general population.

28. The Transition of Moving Home

28.1. Reasons for Moving

A significant portion of the learning disability population lives with members of their family (Blackman, 2003). If a person with a learning disability lives in the family home when a parent dies, this can precipitate a move into residential care (Oswin, 1989 & 1991). Another reason that facilitates moving out of the family home is the fact that the family can no longer continue caring for the person with learning disabilities at home in the way that they previously did either due to old age or because they need support themselves (Thompson, 2002). Usually these moves are involuntary. However, there are cases of moving home voluntarily. People with learning disabilities may want to live on their own or with friends or with a partner. Other reasons include a wish to live with other people of their own age, or a wish to live more independently, live somewhere with more support provided, live with fewer people, or live in a different area (Social Services Department and Housing Department Wandswoth Council, 2006).

In this study, the participants' reasons for moving varied. Most participants moved involuntarily out of their family home. Only two out of the fourteen participants chose to move voluntarily. Usually the main reasons for moving home were changes in life or in family circumstances. As in Oswin (1989 & 1991) and Thompson (2002), the participants' families were unable to look after them and consequently they had to move elsewhere. In general, it seems that the inability of the family to look after the person with learning disabilities is the most common reason for residential transition.

28.2. Choice

Choice can refer to the process by which people come to a conclusion regarding different courses of action which are thought to be available. It is important to emphasize that a person can exercise choice if he/she has at least two options of action and if he/she can influence which option is chosen (Harris, 2003). According to Searle (1983), the essence of choice is a personal awareness of one's own capacity for intentional action.

In this study participants felt they had no choice with regarding their residential transition. The decision to move was usually made by others around them and participants were simply informed about the event. Consequently, there were no options available to them for consideration. This finding was in accordance with relevant literature on residential transition. The limitations on individual choice in moving home are mirrored in a report on residential transitions for older people with intellectual disabilities by the Social Services Inspectorate (1997): 'Inevitably, there will be occasions when it is necessary to move people from one form of accommodation to another' (Social Services Inspectorate, 1997, p. 33). Here, the essential passivity of 'being moved' is clearly stated mirroring some of the findings of this study regarding the participants' lack of choice in the decision making. However, the main issue is who is making the decision to move and under what conditions.

This difficulty in providing the person with learning disabilities with choice is a reflection of several factors. These include the difficulty of determining the views of some people with learning disabilities with respect to complex decisions, the financial constraints which dictate that some preferences cannot be met within available resources, the inherent processes by which decisions are made, including the quite objective responsibilities that service providers have for the person for whom they provide and finally, the nature of the service and type of model about which negotiations are to be made. Though consultations with individuals may take place and change may occur in the best interests of the person, the overall picture is not an empowering one for people with intellectual disabilities when it comes to personal choices like their future residence. This

particular choice should be central to any consideration related to individual respect, choice and decision making (May, 2001).

28.3. Emotions

In Jones' study (2010) about the experience of moving out of the family home for African Caribbean people with learning disabilities, participants reported a variety of feelings during the process of transition including happiness, excitement, fear, anxiety, disappointment, frustration, sadness and anger. Participants often described this as a fluid process whereby they moved backwards and forwards between emotions rather than through a set order of emotional stages. It also seemed that the emotions participants described and the extent to which they felt each emotion was somewhat dependent on the amount of control and choice they had in their residential transition.

There seem to be similarities between the findings in Jones (2010) and the results in this study. Participants in this study often talked about experiencing anger, frustration, loss, anxiety and sadness during and after the process of the move. As in Jones (2010), there did not seem to be any obvious emotional stages and there were links to the amount of control and choice participants had concerning the move.

Another interesting point emerging from the participants' accounts was their difficulty in talking about their emotional process. Although the atmosphere during the interview felt very emotional, most participants seemed to use little emotional vocabulary to express how they felt and most of their statements were brief. Perhaps this finding could be explained with and connected to the learning disability literature. Relevant literature supports that a significant proportion of people with learning disabilities has difficulty in expressing emotion (McAlpine, Kendall & Singh, 1991), especially negatively toned emotions and has an impoverished emotional vocabulary (Bates, 1992).

28.3.1. Loss

Loss was a prominent emotion in participants' accounts. It is important to note that this process of loss that participants described going through almost resembled one of the tasks of mourning by Worden (2001): working through the pain of grief. Participants talked about missing their family home, their loved ones and the possessions that they couldn't take with them. Participants seemed to experience a profound sadness about having moved from their family home. This grief/loss reaction was also mentioned in Fried (1963) and Speller (1988). Both researchers have shown that unwanted and personally uncontrollable change in the physical environment that result in the loss of the principle of continuity, may cause a grief or loss reaction. Such grieving can be longterm. This was also demonstrated in the study by Nanistova (1994a,b) in which it was found that inhabitants of a village who had been forcibly moved in order for their valley to be flooded for a reservoir were still distressed 40 years later. It seems, therefore, that a loss reaction could be paired with forced transitions and perhaps there might be a possibility of this being applicable to this study.

29. In the New Home

29.1. Adjustment

Adjustment to the new home was another process that emerged from the participants' accounts. Adjustment has been defined as 'a reordering of priorities and a reintegration of the self with a renewed sense of self worth' (Naugle, 1991,142). According to the Livneh (1991), adjustment is characterised by confidence, contentment and satisfaction and implies resolution of conflicts and establishment of a healthy new identity (Shontz, 1991). However, adjustment does not mean conforming to the expectations of family or society, but establishment of an inner equilibrium (Luborsky,1994). Adjustment, therefore, is a process that occurs primarily within the individual (Olney & Kim, 2001).

This process of adjustment as described by the scholars above did not seem to occur for the participants in this study. On the contrary, participants reported their struggle to adjust to their new home and described settling down as a gradual process that took some

time. There was a rather forced sense of acceptance in participants' accounts, a sense that they were resigned, simply accepting being in their new home without any choice of going back to their families. It is alarming that people with learning disabilities may even today experience forced adjustments, whose effects can only be detrimental to their emotional wellbeing.

29.2. The Impact of Relationships

A major criterion that has been used in the evaluation of residential services for people with learning disabilities is the integration of this population in the community (Emerson, 1985; Felce, 1988; Dagnan, Howard & Drewett, 1994). There are two types of intergration, according to Wolfensberger and Thomas (1983) and Nirje (1980): the physical and the social integration. Physical integration refers to the actual presence of a person in ordinary settings, whereas social integration to the formation of a range of relationships in these settings. Social integration, therefore, is required in the social environment in the care home. As Reed, Roskell Payton and Bond (1998) said about this process: 'Observing social conventions, while at the same time meeting needs for companionship and social contact, involves new residents in a complex negotiation of their new social world' (Reed, Roskell Payton and Bond, 1998, p. 157).

Social integration seemed to be necessary for the participants' adjustment in the new home. This was expressed in the participants' accounts regarding the impact relationships had on them while residing in the new home. Participants described living with their new housemates as a struggle. Many participants agreed that it was difficult to relate to other people in the care home. Some even described their conflicts with other residents or their dislikes. This finding seems to be in accordance with Forrester-Jones et al. (2002), who clearly stated that problems with social relationships in the care home can be the most difficult aspect of life in the care home, particularly when you have to live with people you do not like, or who do not like you. Similarly, Grant et al. (1995) in a study of older people with learning disabilities living in group homes found that the quality of life of

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individuals was profoundly affected by the nature of interpersonal dynamics within the home. Both these statements seem to reflect the findings of this study.

Participants in this study also referred to the impact relationships outside the care home had on them, that is, their family, their friends and the community. Participants acknowledged having a supportive environment around them that helped them to settle down to their new home. People in the neigbourhood seemed to be available and willing to help them and support them in their everyday life. This finding seemed to differ from the findings in Jahoda, Cattermole and Markova (1990), who concluded that people with learning disabilities participated in more community based activities after their move but had very few opportunities to meet non-handicapped people, leaving them segregated and feeling dissatisfied. Perhaps as years go by, people with learning disabilities are less stigmatised and more accepted within the community.

30. Transition to the New Self

In a study on the social integration of people with learning disabilities after moving to the community, researchers concluded that after the move there was an improvement in the quality of residential provision, in the service users' personal freedom and in their community presence (Ager et al., 2001). It seems, therefore, that people with learning disabilities experience some change after their residential transition. This was also echoed in the findings of this study. All participants talked extensively about the changes that occurred in their lives after moving to the care home, particularly noting changes in their identities. Many participants felt they had grown after their move, being more mature and more independent and capable of taking initiatives.

Additionally, they acknowledged areas for further development i.e. the areas they still needed support in, and identified new learning experiences taking place. Participants also described changes in their mood and emotional wellbeing after settling in to their new home. It seems, therefore, that the residential transition and the new home can have a significant impact on the identity of a person with learning disabilities. As Hormuth

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(1990) supported, choosing to move can represent a change in the self-concept, with the old place becoming a symbol of the old self and the new place representing an opportunity to develop new identities. In both these examples place is considered to be an active part of the construction of a person's identity, representing both continuity and change.

31. The Conceptual Model and its Links to Current Theoretical and Policy Implications

The conceptual model on the experience of moving home for people with learning disabilities that emerged through the analysis of participants' accounts in this study has links to current theoretical and policy implications. From the model we can observe how the experience of moving home impacts on the identity of people with learning disabilities. This model confirms and enriches identity literature, which supports that relocation presents an interesting challenge to identity structure (Hormuth, 1990). In some cases, the move may require people to develop entirely new identities (Deaux, 1992). In other cases, people may try to reconnect their identity to a different set of people and circumstances, maintaining the essence of a previous identity (Ethier & Deaux, 1990). This last notion was confirmed by this study's conceptual model. Participants maintained their identity prior the move and through their experience of moving and living in their new home they made new connections to a different environment and style of living as well as to new relationships (i.e. fellow residents and staff etc). An interesting implication this model offers to identity literature is the fact that participants' identity evolved through this process of transition, adding new elements to their previous identity. A further implication that this model provides us with is the fact that identity literature related to the issue of relocation could apply to the learning disability population.

Furthermore, this conceptual model has significant implications on the literature on the identity of people with learning disabilities. This model confirms research findings by Whitbourne (2005) on adult development and aging and shows that these are also

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applicable to the learning disability population. Whitbourne (2005) suggested that both past and present life experience are linked to one's identity through processes of assimilation and accommodation. She supported that identity assimilation referred to the interpretation of life events relevant to one's current sense of identity. The forms that identity assimilation could take all involve distortion of facts that are inconsistent with one's current sense of identity. Whitbourne defined identity accommodation, on the other hand, as the change in cognitive and affective schemata so that one's sense of identity actually changes. Whitbourne supported that a realistic appraisal of one's identity and life experiences is involved in the process of identity accommodation. The individual seeks a kind of identity homeostasis, in which experiences and identity are consistent or in balance. However, Whitbourne claimed that adjustments become necessary when one's identity does not match an experience. Hence identity assimilation and accommodation processes come into play. The conceptual model of this study could be connected to this theory and add to its applicability to the learning disability population.

Both identity assimilation and accommodation can take a variety of forms. Forms of identity assimilation give the individual positive information about the self, even if this information is inaccurate. Identity assimilation often involves twisting one's perceptions of experiences so as not to have to change one's views of the self (Whitbourne, 2005). Through the conceptual model we can observe that, although participants in this study found the process of moving and the new home a challenging experience associated with unpleasant emotions, in the end they reported positive changes to their identity and feeling positive about their current circumstances and moving home. It may be possible that participants protected their identity by twisting their perception of their experience of moving home by having a more positive outlook of how this experience influenced them.

The process of identity accommodation involves trying to arrive at a realistic appraisal of the self in relation to experiences; this process may ultimately result in changes to one's sense of identity. Identity accommodation often involves acknowledging areas of personal weakness and responding to them (Whitbourne, 2005). In this conceptual model

we can observe how participants acknowledged their personal weaknesses and identified areas where they needed assistance in relation to living in their new home.

Moreover, this model has implications for services dealing with people with learning disabilities. It can inform the practices used in care homes and guide staff's communication with the service users with an emphasis given in promoting and enhancing empowerment and choice. This is particularly important, since there are still barriers that prevent the empowerment of the people with learning disabilities in the services in the UK. The report *Improving the life chances of disabled people* (Prime Minister's Strategy Unit, 2005) discussed two main barriers: support is often not fitted to the individual, rather disabled people are expected to fit into existing services; services tend to focus on incapacity, inability and risk, with the result that dependency is created. Indeed, this report identified a 'culture of care and dependency' (Prime Minister's Strategy Unit, 2005,p. 73) in health and social care services, in which those with 'significant cognitive and/or communication impairments are particularly at risk of being denied choice and control in their lives' (ibid.,p.78). *Improving services, improving lives* (Social Exclusion Unit, 2005) recognizes that the interactions between 'disadvantaged people and frontline staff are crucial to how successful services are in meeting people's needs' (2005, p. 57). Empowerment is not just about choosing to take this type of support rather than another, but it is mainly about what happens between people moment by moment, in the mundane details of everyday interaction (Finlay, Walton & Antaki, 2008). This conceptual model, therefore, sheds some light into the internal world of people with learning disabilities and informs staff's attitude and behaviour in order to provide support to those moving to the care home.

Furthermore, this conceptual model assists in the promotion of a person-centred approach in care homes and in the process of transition to the care home with an emphasis on the service user's identity. Central to a person-centred approach is a change of identity for people with intellectual disabilities, from that of relatively passive recipient of services, advice and education, to that of an empowered and rational consumer of services

(Antaki,Walton & Finlay, 2007). This model acts as a reminder of choice and control people with learning disabilities should have in the process of transition to a new home.

Additionally, this model has implications for policies and policy-making regarding accommodation and housing for people with learning disabilities, since it shows how moving home can influence the identity of this population. This model could inform the making and the revision of guides for housing options for the learning disability population (e.g. Pannell & Harker, 2010). It could also inform housing strategies, promote choice in the transition process, improve residential care for the learning disability population and assist in service's good practice. It could also be included in *Valuing People Now: The Delivery Plan 2010-2011: 'Making it happen for everyone'*(HM Governement, 2010) in order to support further the plan's aim to work towards resolving barriers to changing residential care.

In addition to the above, and taking into consideration that the present research has provided evidence regarding the identity change of the people with learning disabilities when moving home, the issue of relocation should be approached with the outmost sensitivity from the part of services and be supported by clear policies. People with learning difficulties appear to go through a process of redefining their identities, which unavoidably creates anxiety and uncertainty. Therefore, services operating from a person-centered approach, should provide both the necessary time and space for these people to process these changes. One way this could be achieved, is by offering one to one counselling throughout the process so that the individual gets adequate support to deal with the separation from their previous location and the anxieties of moving to a new place, during the relocation to manage to cope better with the practicalities, and after the relocation to process any residual feelings of loss and the emergent new identity. Relocation Groups could be another way to help individuals cope with the stress of relocation and the changes they experience in themselves. When feasible, individuals who go through this process could be offered the opportunity to meet each other in the context of a safe group and through the help of a facilitator to be allowed to exchange experiences. Further suggestions for clinical practice follow below in the section entitled *Implementation of the research findings* (p.151).

32. The Original Contribution of this Research

This research makes an important contribution to the area of moving home and learning disability because it viewed this topic from the scope of identity. Not only did this study explore residential transition, but it also gave insight into the transitions happening in the identity of people with learning disabilities while moving home. This research has also shed light into participants' emotional process before, during and after transition occurred, giving us invaluable information of their inner world.

Additionally, this study presented some originality in its methodology. Qualitative research was conducted with a larger number of participants (fourteen) than the one suggested for professional doctorates (Smith, Flowers & Larkin, 2009). Furthermore, this study's criteria allowed candidates of some learning disability levels[8] to participate bringing breadth and variety to the data.

Another original contribution this research has to offer involves the overall research strategy. Agency and empowerment were the main themes that drove the research strategy of this study. These were evident in the study's goal to give voice to people with learning disabilities and to represent their experience as closely as possible handling and describing their accounts with care. Additionally, this research was driven by the wish to empower individuals with learning disability and allow them choice and control in the interviewing process. This was facilitated in the way participants were recruited (participants identifying themselves as having a learning disability) and how the interview process was conducted (with the use of process consent throughout the data collection, allowing participants to choose the names they wanted to be represented by in the data etc).

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[8] As explained in Chapter 2: Methodology and Procedures (p.54) and later on in Study Limitations (p.160), only verbal individuals could participate in this study's interviews. This inevitably excluded non-verbal individuals from participating in this study.

33. Implementation of the Research Findings

The results of this study have several implications for clinical practice. Professionals should bear in mind the main findings of this research as this should help them to interact with people with learning disabilities in a more compassionate and empathic way in their clinical practice.

During the process of conducting this research study I realised that I had not encountered a research piece that would share any general observations in depth about the experience of moving home for people with learning disabilities and that would incorporate as well guidance for care home staff and clinicians. This section is an attempt to fill in that gap combining information from literature I have come across as well as my own observations from this study's research findings and from the participants' stories.

33.1. Personal Observations

Throughout the process of this study and its outcomes, I made several surprising and unexpected observations. The first thing I did not expect to experience was the intensity of expressed emotions from the participants' interviews. It seemed that moving home was a 'hot' topic for most participants, especially in terms of their choice to move. I felt deeply moved not only during the interview process, but also during the process of analysis, when I worked closely with the participants' use of language. I was also surprised by participants' openness and clarity concerning their emotional experience. Participants were not at all defensive or apprehensive talking to a stranger, like me, about issues so personal and, at times, painful to them.

Moreover, another surprising observation was that participants seemed to put more emphasis on the positive/pleasurable aspect of their moving experience and tried to refer less on its negative/unpleasant aspects. It seemed as if participants avoided talking about the negative/unpleasant aspects of their experience. Some participants even tried to "make it ok" by referring to their present situation stating that things now were ok for them. Perhaps this kind of response could serve as a defense mechanism protecting

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participants from the pain they experienced when moving home. This hypothesis was indeed a very interesting point for me, since it could suggest the use of defence mechanisms for people with LD, and the possibility that psychoanalytic theories on ego defense mechanisms could be applicable to this population too. This observation seems to be confirmed by the findings of Newman and Beail (2010), who concluded that adults who have a LD use a range of defences in psychotherapy and have particular defensive styles.

33.2. General Observations and Suggestions on the Experience of Moving Home for People with Learning Disabilities

It is only natural to experience an emotional upheaval when moving home. People with learning disabilities are as sensitive to transitions and change as other populations but they express their emotions differently. Some may respond to such transitions by clinging to their known routines and by sudden and delayed inexplicable behaviour, whereas others may appear more withdrawn. Practitioners working with this population need to be mindful of the emotional process of this population (ie. anxiety, fear, confusion, uncertainty, sadness, joy etc) and give them time to adjust to the new environment. For successful adjustment to take place, people with learning disabilities - like other populations - need their time to say goodbye to their old home before embracing the new home. Professionals need to understand that the transition period is vital for adjustment and that its duration might vary depending on the move and how well the person was prepared in advance.

Some people with learning disabilities may experience profound loss when moving from their family home, as this study has shown. The person with learning disabilities might experience phases of mourning, going through the phase of accepting the reality of the loss, experiencing the pain and adjusting to the new environment while making external and internal adjustments at the same time (Worden, 2001). During this process professionals need to be patient and understanding, allowing people with leaning

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disabilities to express their feelings. Offering counselling sessions focusing on the transition might assist the adjustment process.

There are several factors that could aid adjustment in this population. It seems that a common phenomenon for many participants in this study was the tendency to try to adjust to a new situation by making it familiar. People with learning disabilities, as we saw in the analysis, when they first moved to their new room, tried to put their mark on it and make it their own. It will be helpful to provide people with learning disabilities with the choice of personalizing their own room and participating in the decision making regarding the decoration of the care home they live in.

Apart from personalizing their own room, efforts need to be made, if possible, for the person with learning disabilities to experience some stability during their transition to the new home by maintaining some aspects of their life in their family home i.e. by continuing to attend the same college or the same day service. It might be helpful for this population to maintain frequent contact with their pre-existing relationships i.e. family, friends, keyworkers, teachers and services they used to attend. Also, professionals need to be mindful of the safety and security feeling attached to their routines and should thus allow continuity between the routines followed in the family home and the routines of the care home.

At the same time it is vital for professionals to focus on the service user's social integration in the care home and in the community. People with learning disabilities would probably benefit from a gradual introduction of different things in their everyday schedule, allowing them time to digest each new activity before moving to the next one; this would also include extracurricular activities. Another important aspect of the service user's social integration involves the relationships among fellow residents and staff. Srivastava (2001) stated that social relationships may make or break community placements for people with learning disabilities; specifically, relations with fellow residents and the staff is of utmost importance in their adjustment. In order to support the service users' social integration with fellow residents, a thorough assessment of the service users' profile and needs is needed prior to moving to the care home. In this way

professionals could predict whether this person is likely to adjust to the care home environment and whether he or she could fit into the group of residents. Should the assessment be successful, preparation regarding the person's transition needs to follow. Arranging visits and overnight stays in the care home could provide the person with learning disabilities with an opportunity to familiarize him/herself with the environment and meet the other residents. Furthermore, organized events such as housewarming parties, care home meetings etc could assist the new resident in getting to know the other people and establishing friendships or making contact with others.

33.3. Observations and Suggestions for Care Home Staff

Professional staff within community services and care homes plays a significant part in the everyday lives of people with learning disabilities. Staff is usually the first point of contact for the residents and frequently acts as the first point of support. However, staff may receive little training and unqualified staff predominantly learns though observation of their peers, which can result in some poor practices , that even worse become, ingrained in the home care context. (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection, 2006, p.64; Owen, Hubert and Hollins, 2007). Therefore, it is vital for care home staff to receive tailor-made training on the transition of people with learning disabilities to the care home and how they experience such a transition. It is also pivotal to offer supervision and support to staff in order to ensure better quality of service and care to the service users in the care home. Moreover, staff needs to allow time to get to know the new resident and understand his/her behaviour without making assumptions straight away. Staff needs to be aware of their attitude towards residents and of the organisational structure and culture of the care home they work in.

33.4. Recommendations for Professionals

The following clinical recommendations emerged from this study in relation to the provision of appropriate support.

- Due to the high proportion of sudden and unprepared moves, earlier and better monitoring of families should take place so that support can be offered when it is needed rather than only in times of crisis and/or of unexpected events.

- Support should be offered in helping people with learning disabilities and their families plan for moves in advance. This may need to incorporate an educational component so families and service users can understand the risks associated with delayed planning.

- A thorough assessment of needs should be carried out so that individualised support can be offered in a constructive way, e.g. by teaching rather than doing everything for the participant. The practitioner should gradually reduce the level of support until the person can move through all the tasks independently.

- People with learning disabilities should have their own voice and have their voice heard. This was a frequent issue for participants, especially around choices, and a main complaint about their life in the care home. This may indicate a need for advocacy when planning transitions.

- Service users need to have control over the decision to move home. In order to do this, professionals may need to become more proactive in providing information and options to the person with learning disabilities so he/she knows what services are available.

- There should be a continuity of care with professionals i.e. service users should not be passed from one person to another without being told and without having the opportunity for planned endings. People with learning disabilities may have experienced many losses and this fact needs to be taken into consideration when planning endings.

- Professionals should recognise that residential transitions can signify emotionally vulnerable times for service users regardless of whether or not they have had an active role in planning. Therefore, professionals need to offer emotional as well as practical support to service users throughout the transition period.

33.5. Observations and Suggestions for Services

According to Owen, Hubert and Hollins (2007), there were several issues that had made difficult the transition of people with learning disabilities in their new home: a lack of involvement and support during the transition process, failures in the transmission of information to the new homes, and variations in the organisational structure and culture as well as in staff's training and experience. In order for these issues to improve, there needs to be extensive work within the social and health services for this population. Heslop and Abbott (2008) supported the necessity of continuity for young people with learning disabilities, the need for creativity in minimizing the effects of distance and good forward planning in order to help young people with learning disabilities to move on in life. People with learning disabilities were likely to be at risk of poor transition, if there was poor planning and ineffective links in between services and not enough information about available options concerning their transition. This could be resolved with the development of a centralised information system that can be available between all services in the country, distributing information and minimizing the distance.

Furthermore, Harding (2004) suggested that in order for effective change to take place, organisations need to proceed through the steps of *awareness, interest, desire* and *action*.

At the *awareness* stage there is pressure for change and active commitment towards it. Awareness is evident in organisations from policy documents and practice guidelines for transition planning that have been developed for this purpose. However, development needs to be promoted in the *interest* phase, where highly motivated members of staff have a shared vision about the transition process and outcome for the people with learning disabilities and work in partnership with each other. Services, therefore, need to work more on long-term planning, not just on short-term.

In order for services to engage in more effective long-term planning for residential transition, there are several steps that they need to follow in order to accomplish this. These are:

- *Preparation*: This step would involve exploration of choices and taking into account other changes that happened in the life of the person with learning

disabilities. Additionally, it would provide advice prior to the move. Planning or preparation groups could be effective for this purpose (as suggested in Banham, Garret et al., 2003).

- *Development of multi-professional links*: This step involves engaging the entire system of people working with the person with learning disabilities in close cooperation so that transition can be addressed on multiple levels,

- *Working on goodbyes*: This step involves working with the person with learning disabilities on transition in terms of planned endings and goodbyes. There are various tools and interventions on addressing loss and saying goodbye that could be used by professionals, such as life history workbook, memory boxes etc

- *Formulating new attachments*: This step involves establishing relationships with staff, advocates, professionals, keyworkers in the new home that will facilitate the transition.

- *Entering the new community*: This step involves introducing the person with learning disabilities into the wider community near the care home, that is facilities, day care services, social clubs etc. It is a step that enhances considerably the service user's social inclusion.

- *Maintaining links*: The final step involves maintaining contact with the previous home and the previous relationships of the person with learning disabilities, so that instead of an abrupt disruption there is a smooth continuation between the past and the future and a safe evolvement of the person's identity.

Finally, multiagency transition planning should be available to all people with learning disabilities, including young people, as well as, older adults. In the past there were concerns that people with learning disabilities, as they get older, are at risk of being disadvantaged, not only because of their disabilities, but also because of their age. Service providers should offer choice and take their direction for facilitating opportunities in the community in the same way that they would for much younger or middle-aged people. This also applies to residential provision and day opportunities (May, 2001).

33.6. Choice and Decision Making

The participants' choice was a theme that was extensively discussed in participants' accounts. Most participants felt that they did not have a choice in the decision to move home and felt they had no control over the transition process. Choice and control over decision making is significant for people with learning disabilities, since it can increase satisfaction and wellbeing when moving home (Andersson, Pettersson and Sidenhall, 2007). Services, therefore, need to include the views of people with learning disabilities in decisions around residential transition.

In order to facilitate choice and decision making for people with learning disabilities, services should provide this population with a range of experiences relevant to making choices, and the time to explore and understand the different options (Harris, 2003). More specifically, services should:

- Organize the environment to highlight options
- Provide social support, and
- Provide experiences of making choices which are relevant to the person's lifestyle.

Talking mats could be used with people with learning disabilities as a tool to express choice and decision making in transition (Cameron & Murphy, 2002). Their advantage is that they can be used even with non-verbal population, as well as, with people with severe learning disabilities.

An important factor that one needs to consider is the feasibility of implementing these suggestions at a time when services are facing cuts in funding. These suggestions do need a considerable amount of time to be absorbed in order to be implemented. In my view the above suggestions mostly require a change in the system's philosophy, not only in terms of funding. The whole system needs to incorporate another perspective in the planning of services and to include a strategy for transition beginning before adulthood. We need to allow time for this new perspective to develop and take it step by step since transitions are generally difficult, even for organisational systems.

34. Implications for Counselling Psychology

This research has presented the implications for practice for Counselling Psychologists. Through this research Counselling Psychologists can gain an understanding of the experience of moving home and its impact on the identity of individuals with learning disabilities. Practitioners may have in mind these themes when they provide individual or group therapy to people with learning disabilities. It will also be helpful for practitioners to know about the difficulties and the challenges this client group faces, as well as, the coping strategies that are employed when working in a community setting with this population. The themes that emerged from the analysis can be taken into consideration and explored when working within those settings. In particular, consideration could be given to the sense of struggle that often appears to dominate such transitions, the desire for independence, the need to feel heard, and the way in which transitions can make people with learning disabilities feel emotionally vulnerable.

Counselling psychologists may also play a vital role in providing support to carers or assist and empower carers to provide support to people with learning disabilities during this process of residential transition. Practitioners may also find this model useful when they provide training on residential transition to people with learning disabilities, their carers and services' staff.

This research study may also provide Counselling Psychologists with the necessary insight that will help them participate better in the decision making and the forward planning of community residential settings for people with learning disabilities, since it provides the therapist with a good perspective on the setting and the transition to the setting.

Moreover, this research could be used as part of training for Counselling Psychologists that are interested in this specific field. Dryden (1994) highlights the importance of exploring educationally how we could modify counselling training to make counselling accessible to all clients.

35. Study Limitations

In the process of exploring the experience of moving home for people with learning disabilities and its impact on their identity, certain study limitations emerged regarding the sample, the scope of the interview schedule and the data validation.

35.1. Sample

A study limitation may rise from the criteria for participation. A formal diagnosis of learning disability was not obtained and classifications regarding their degree of learning disability were not made for the participants. Neither of these was considered relevant in conducting this research. Taking into account the participants' voice in this research and giving them the right to identify themselves as people with learning disabilities was very important . The criterion of having visited a specialist or a service for people with learning disabilities in the past was the one that suggested a degree of impairment and was considered to be a sufficient condition for the purposes of this research. Participants were not excluded on the basis of their severity because this does not limit the significance of their experience of moving home. Should a formal diagnosis of learning disability be necessary for this study, a possible way forward would be to recruit both through Social Care and National Health Services following the research approval pathways of each service.

A further limitation of this research is related to the recruitment of the participants. Several difficulties arose in the process of recruiting female participants. Although the recruitment process was open to participants of both genders, the final sample consisted mostly of male participants (nine) and only five female. It is unclear whether this is the result of the services suggesting more male participants or whether indeed more male participants came forward for this study. It is possible that the difficulties in recruiting females may represent a tendency that more male than female individuals with learning disabilities move out of the family home. The ratio of male to female service users living outside the family home has not been reported in the available literature and so it is difficult to know whether there is a gender difference in the use of care home services. This would constitute an interesting area for future research in the field.

The sample used in this study was relatively homogeneous as it is suggested by the employed methodology. All participants acknowledged having a learning disability and had all moved out of the family home. However, there were factors gave to the data some variability. Participants varied in the amount of moves they had experienced in their lives ranging from one to 6 moves. Additionally, four participants were currently into the independent living scheme and had their own flat and one of them was married living with his/her partner. A way to minimize variablity would be to be more specific about the number of moves prospective candidates would have experienced and about their current living arrangements. Perhaps deciding to recruit, for instance, only participants that would have experienced one or two moves and still reside in the care home premises would increase sample homogeneity.

There was also some variation among participants in the amount of time that had elapsed since the first move out of the family home, ranging between 6 months and forty three years before. This has implications not only for the homogeneity of the sample but also in terms of the accuracy of the participants' recall. However, research has shown that although people with learning disabilities can have memory difficulties linked to their cognitive impairment, they have better autobiographical than semantic memory (Pennington & Bennetto, 1998; Kebbell & Hatton, 1999) and so are able to recall past events in some detail. Some participants did appear to struggle in their recall of the process of the initial move from their family home when asked for details. However, all were able to convey a strong sense of how they felt at the time and the reasons for moving home. It is essential to emphasize that in this study the focus was on the participants' subjective experience and their meaning-making in terms of moving home and not on the accuracy of events. Rather, the focus was on the emotional quality of their experience. Following from the previous criticism about sample variability, a way perhaps to increase sample homogeneity and to tackle the issue of participants' recall would be to establish a specific time period elapsing since moving out of the family home.

Another criticism of this research rests with transferability. Since only a small number of individuals participated in this research, their experience may not be transferable to the general population of people with learning disabilities facing residential transition. Although the results are less transferable, gaps in the existing literature regarding the experience of moving for people with learning disabilities and its impact on their identity justify this study. In support of this, Ferguson, Ferguson and Taylor (1992) note "no one person's life can be wholly representative of an entire group, for each individual is unique. Yet I feel that a detailed examination of one's life may provide insight into the larger question of how 'mentally retarded' individuals are perceived in societies" (Ferguson, Ferguson and Taylor, 1992, p. 175). Perhaps the issue of transferability could have improved in a study that would combine both qualitative with quantitative methods. In addition to participants' interviews, questionnaires on moving home could have been sent to a larger sample of the learning disability population in order strengthen results' transferability.

Finally, this study allowed participation only to those individuals that were able to verbally express themselves (meaning individuals that had some degree of verbal ability-not necessarily having high verbal ability). Having chosen IPA as my research method required participants to have some degree of verbal ability, both receptive and expressive in order to take part in the interviews. Including only verbal participants makes it questionable to generalise from research findings across the full learning disability population. People with learning disabilities with verbal skills may not necessarily be representative of the whole client group. Allowing only individuals that had some degree of verbal ability to participate was done solely due to my inability to assess participants in other non-verbal ways i.e. by using Makaton, Talking Mats or other tools. This, therefore, excluded non-verbal members of the learning disability population. Despite that, the experience of the fourteen verbal participants could offer some insight about the moving experience of other adults with learning disabilities and to some extent it may be representative, although this cannot be assumed.

Elaborating further on the above criterion, it should be noted that most prospective candidates that came forward for the interviews had good verbal skills. This could be due to the way care home staff or keyworkers communicated and/or advertised this research to prospective candidates (after the organisation received the research pack). There may be a possibility that care home staff did not inform all service users about the research, but approached only the ones that believed they could participate in this study - perhaps the ones that could respond to the interview schedule. The above issue could relate closely to issues around the amount of choice and control people with learning disabilities are given, as it has been discussed in current reports. According to the report *Improving services, improving lives,* disabled people can feel 'steered towards choices made by other people' (Social Exclusion Unit, 2005, p. 64). Sometimes staff, managers and parents try to control the lives of people with learning disabilities (Learning Disability Taskforce, 2004).

Since this possibility only came to my mind after the interviews took place, I tried to consider possible ways that would have made the research more accessible to a bigger audience of prospective candidates allowing more services users to be informed about it and thus to have the freedom to chose or not to participate. A possible way to deal with this problem could have been my direct presence in the care homes from the beginning, in the recruitment process: I could have considered asking for permission to organise a presentation to each care home that all service users could have attended. In this way, prospective candidates would have had the chance to meet me in person and would have taken the information about the research directly from me without the need for a mediator at this stage. Perhaps this idea could be used in future studies for the stage of recruiting participants from this population.

Another suggestion to further improve this research would be to use alternative forms of data collection for a potentially wider sample that would include individuals who may not have the verbal skills for conventional interviewing. Creative approaches (such as the ones described by Read (1999b)) could be extremely useful for data collection. These include, among others, drawings, pictorial guides on moving home (such as *Moving*

House (Wilkes, 2005)), photographs of the individual with learning disabilities (family photographs, photographs of the family home and the care home etc), poetry (poems that the participant wrote, other people's poetry, even song lyrics from a favourite song could assist in emotional expression) and talking mats (Cameron & Murphy, 2002). There are also other methods of data collection used in IPA sharing some of the advantages of interviewing that could be useful for candidates with non verbal skills provided they could read and write. These include electronic e-mail dialogue and diaries (Smith, Flowers & Larkin, 2009).

35.2. Interview Schedule

On further reflection there were certain issues that were not adequately explored by the interview schedule, which may have led to the generation of a higher quality data had they been included. For example, it would have been useful to have further explored the degree of choice participants had over the move, the relationships with their family prior to moving home and their relationships with the staff and fellow residents in the new home.

Additionally, the interview process used in this study could have been designed differently in order to enhance the communication of participants and help them to elaborate on their answers. The use of visual aids including emotion cards could have assisted the participants to communicate in a more concrete and accessible way with the researcher. Furthermore, it might have been useful to create a timeline along with the participants at the start of each interview as a way of helping the participants to develop a sense of time and sequence of events around their experience of transition or even perhaps a fixed point for the duration of the interview. Having this concrete timeline to look at and reflect upon may have helped the participants to feel less in the spotlight and more able to make meaning of their experience at the time of the interview.

35.3. Validation

This study would have also benefited from involving the participants in member or respondent validation (Henwood & Pidgeon, 1992; Smith, 1996; Lyons & Coyle, 2007). Following the analysis of the transcripts, the emerging themes could have been fed back to participants and they could have provided input on whether the themes adequately summarized their experience of moving home. Consequently, their responses would have been incorporated into the final themes.

Although there is some value in this strategy, IPA supports that some of the interpretations made by the researcher will not be in the participants' awareness and therefore cannot be verified by the participants (Smith, Flowers & Larkin, 2009). On the other hand, there could be a possibility that in not including the participants' perspective, common stereotypes and assumptions about this group of individuals could be reinforced. In order to outbalance this possibility, extra care was taken in reporting the results to the participants in a respectful and compassionate way at the end of the research, welcoming the possibility of any feedback.

36. Future recommendations

The findings presented in this study give practitioners and other professionals working in the learning disability field some understanding of the experience of the people with learning disabilities during the process of moving out of the family home and its impact on their identity. However, further research could be conducted on this topic in order to extend these findings in the following ways:

- Interviewing carers and staff to see how their experience of the person with learning disabilities moving out of the family home impacts upon them and what resources they need in order to support the person during his/her transition to the care home
- Carrying out longitudinal research which allows the experience of transition to be discussed as it happens in all stages

- Using discourse analysis or other qualitative approaches to explore the type of language that is used by people with learning disabilities when they are describing their experience and their identity

- Conducting research with non verbal participants in order to investigate their experience too and reflect upon how it might compare to verbal participants

- Investigating specific issues that may be important in the experience of transition, such as the reasons for moving, the preparation before the move, the degree of choice the person with learning disabilities had and any formal interventions employed to cope with the difficulties associated with moving home

- Researching the effects of specialized training given to care home staff and carers in order for them to support people with learning disabilities moving home in the scope of developing a standardized training programme for carers and staff

- Researching the development of standardized training and tools preparing people with learning disabilities to move home

- Involving people with learning disabilities in the more intellectual and analytical stages of the research process. For example, in Tuffrey-Wijne and Butler (2010), one researcher with learning disabilities was included in analysing the data of an ethnographic study of people with learning disabilities who had cancer. The researcher with learning disabilities was provided with extracts from the research field notes, and was supported to extract themes which were cross-compared with the analysis of other researchers. The researcher with learning disabilities coped well with the emotive content of the data and with the additional support provided he was able to extract themes that added validity to the overall analysis. His contribution complemented those of the other researchers.

37. Practitioner-Researcher Reflections

Carrying out this research project has been an unpredictable and at times difficult process. Although I had anticipated that participants would have experienced difficult events such as loss during their moving out of the family home, I did not expect the intensity of participants' emotions in their descriptions. I expected participants to

emphasize more the practicalities of the move. Although this was discussed by some of the participants, it was not observed in the majority of the participants' accounts. Listening to some of the most difficult experiences had a great emotional impact on me, but I was also filled with a huge amount of respect for the resilience participants had shown throughout their experience of moving home and for managing to continue with their everyday life.

38. Conclusion

This study provides an insight into the way in which people with learning disabilities experienced their moving out of the family home to a care home. Although the number of participants who took part in this study was relatively small, the method of analysis allowed for an in-depth analysis of the data and for key themes to come out. These themes describe and interpret participants' experiences of moving out of home but there are also themes that go beyond the experience of moving home and represent issues that are prominent in many other aspects of the participants' lives.

Although the findings cannot be generalised to the learning disability population as a whole, they should be considered by professionals when working with this group and can be used to inform their therapeutic practice.

Our aim should be to educate the general population from early on in their lives to accept individual differences, strengths and weaknesses and support weaknesses with existing strengths. It should take the form of a more general attitude rather than a specific, narrow focus on people with learning disabilities because this would avoid stigmatisation and discrimination (that can take place even in the name of special or appropriate support) and would allow any member of this population to be treated as equal to any other individual in society. Within this new context, difference would not be the cause of separation and segregation but of a respectful and ethical living together.

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Part C: Professional Practice

Title: Working with transition and change: Psychodynamic Counselling with a Client with Learning Disabilities

1. Abstract

This client case presentation aims to describe the therapeutic process of a client with learning disabilities with issues around her relationship with her parents, her disability and her degree of dependence from her family. This case study explores the assessment and formulation of Nadya's presenting problem using the psychodynamic approach. In this section the client discusses her decision to move out of the family home and the process of her transition from her family home to the care home. This case study explores how transition and change were addressed and managed in the course of therapy.

2. Working with Transition and Change: Psychodynamic Counselling with a Client with Learning Disabilities

3. Introduction and the Start of Therapy

3.1. Rationale for the Work

I have chosen to present this case as it illustrates the beginning of my work with people with learning disabilities. Therefore, the case of Nadya[9] is very significant for me because it constitutes a milestone of my period of learning how to work with this client group and its emerging issues. This client study is also an attempt to work with issues such as transitions and change that are very prominent in everyday life. Another interesting point of this case study is related to the client's decision, during the course of therapy, to move out of the family home.

3.2. Summary of Theoretical Orientation

I have worked with Nadya using the psychodynamic approach. The concept of *psychodynamic* refers to the active unconscious processes within the psyche. The goal of this approach is to enable the movement of these feelings into consciousness and to alleviate any presenting distress connected to these feelings (Hodges, 2003).

The therapeutic frame involving time and space and the development of a safe and firm basis for therapy (Gray, 1994; Luca, 2004; Connor, 2005) also contributes to a 'holding environment' (Winnicott, 1960) in which the therapeutic encounter takes place. Some fundamental tools used within this approach are the free association method (Jacobs,

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[9] All names and identifying information have been changed in order to maintain confidentiality.

1998), the interpretation, transference, resistance, dreams and the unconscious fantasy (Mander, 2000).

The core of the psychodynamic approach is the unconscious, the processes of transference and countertransference and a range of defences. Sigmund Freud (1910) was the first to talk about the unconscious conflict that skips one's awareness and about processes of transference and countertransference that appear within the therapeutic relationship (Casement, 1990; Clarkson, 1995). Freud described transference as the process in which psychological experiences are revived from the past and they are replayed in relationships in the present (Freud, 1912) and these unconscious feelings and experiences are also re-enacted in the therapeutic encounter. Countertransference is the therapist's "conscious and unconscious reactions and responses to the client" (Hodges, 2003, 25). Alvarez and Reid (1999) argue how essential it is for the therapist to be aware of his/her own responses to the client, especially when the client is less verbal, and to be able to use countertransference successfully. In this way, the therapist can learn to recognize patterns and how tiny changes in his/her behaviour can elicit changes on the client.

The dynamic concepts of transference and countertransference were particularly prominent in my work with Nadya, a young woman with learning disabilities. There is also a great emphasis on these processes, especially in therapy with this client group, since they may have a more restricted vocabulary and may be less able to verbally communicate their experience to the therapist. Thus, great attention is given to all aspects of communication e.g. eye contact, body movements, tones of voice, since they can provide vital information about a client's inner world (Hodges, 2003).

Another prominent theory in the psychodynamic approach is Melanie Klein's theory knows as object relations theory. By observing children's play, Klein argued that children develop internal representations of relationships with significant others and this affects their everyday interactions. Klein was the first to elaborate on the processes of

idealization, splitting and projective identification, where the infant tries to connect to an external object by projecting good or bad aspects of him/herself (Mitchel, 1986).

Defence mechanisms also play a vital part in the psychodynamic approach and keep us from developing a more conscious awareness of what the unconscious contains. However, it is useful to be aware that defences are not necessarily problematic and that they can protect the client from distress and uncomfortable feelings emerging in everyday life (Hodges, 2003).

In addition, Bion's process of *containment* is essential in the psychodynamic approach. Bion perceived the mother or any carer as a *container* and the infant as being *contained*. In this process the client can take back inside and introject modified and processed feelings that are initially held and contained by the therapist (Bion, 1962). For clients with learning disabilities containment is of great importance. Bicknell (1983) views the birth of a disabled child as a bereavement (a loss of a 'normal' child) and as a shock that needs to be processed. Since parents of disabled children have to manage their own feelings, it may be difficult for them to be able to contain their own feelings and be fully available to their infants. This can also occur because parents have to make sense of their child's difficulties and their responses, in addition to the containment of the infant's emotions and projections (Hodges, 2003).

In general, many misconceptions exist about how verbal skills are necessary in order for a client to benefit from the psychodynamic therapy and at times people with learning disabilities may be thought to be 'unwelcome' for this approach (Hodges, 2003). However, various professionals have used this therapeutic method with people with learning disabilities and found it successful in addressing the feelings and the issues of this client group (Symington, 1981; Bicknell, 1983; Sinason, 1992; Sinason & Hollins, 2000). Stokes (1987) advocates how cognitive and emotional intelligence are not necessarily linked and that they can exist independently of each other. Nadya was able to develop emotionally during our therapy despite her mild learning disability.

Apart from traditional talking therapy, there is also the potential to work with this client group using alternative techniques that could be combined with the psychodynamic approach. These creative ways of working (such as the ones described by Read (1999)) could be extremely useful for 'interviewing' people with learning disabilities during the process of therapy and can assist in the client's understanding, communication and emotional expression. Practitioners could use visual means such as artwork (i.e. drawings), pictorial books (i.e. *When Mum Died/ When Dad Died* (Hollins & Sireling, 1989/1994) used for bereavement issues; *The Way I Feel* (Cain, 2000) used for emotional expression etc) and photographs. These are means to encourage clients to think about their feelings and acknowledge the feelings they long to express. Other ways of working include memory books, poetry (i.e. poems that the participant wrote, other people's poetry, i.e. *Know me as I am* (Atkinson & Williamson (1990)), even song lyrics from a favourite song) and talking mats (Cameron & Murphy, 2002).

3.3. The Context for the Work

I saw Nadya at a counselling service specializing in people with disabilities when I was beginning a placement as a honorary counsellor. The Service's orientation is psychodynamic and individual supervision is provided forthnightly by an accredited psychotherapist. Clients are offered a variety of contracts depending on their needs and there is the possibility of seeing clients in other venues such as in Day Care or Community Centers provided that prior arrangements are made. Counsellors are responsible for making the first contact with their clients and for the administrative work required e.g. letter and report writing, collecting fees etc. Nadya was seen in the Service's counselling room.

3.3.1. The Referral

Nadya was referred by the director of a service for young people with learning disabilities for having depressed mood. Although Nadya had counselling in the past in that context,

she reported that she had experienced her counsellor as passive and not being able to help her move through her issues of dependency. However, Nadya was willing to try counselling once more after having experienced low mood and anxiety after her kidney transplant (see biographical details of client). Nadya was assessed by the Service's Coordinator and also my supervisor prior to counselling.

3.4. Convening the First Session

Nadya was a small well built 21-year-old white British woman, dressed neatly and casually. Sitting in the waiting room beside her father, she seemed uncomfortable and uncertain. When I went to meet her (as I will explain later on, Nadya was partially sighted), she sought for my hand to lead her inside the room until she was able to sit in the chair. Although obviously nervous, Nadya explained to me in a shy voice but clearly the reason she came to see me, smiling often and maintaining frequent eye contact. Being aware of her eyesight problems, I wondered to which extent she could see me, or the surroundings and to which extent she could find her own way independently of my help.

3.5. The Presenting Problem

Nadya came to counselling in order to address her dependency on her parents, which she described as her source of entrapment and isolation. Consequently, Nadya expressed the desire to work around her need to move out from her parents' home and be more independent. In addition, Nadya informed me of her worry and anxiety concerning her transplant that has subsided significantly due to satisfying checkups before our first session. She also disclosed having a low mood because, even though "she was almost an adult", due to her eyesight ("being blind") and mobility problems she had limited opportunities to socialize with people of her own age and to have outings in places where she could meet others. Having in mind relevant literature on the difficulties people with learning disabilities and physical and sensory impairment encounter in social

relationships (Bender & Smith, 1990; Kavale & Forness, 1996; Pearl et al., 1986; Nabuzoka, 2000), I was able to understand Nadya's struggle.

Dependency needs is one of the common issues and themes that arise in the psychodynamic work with people with a learning disability (Sinason, 1999; Sinason & Hollins, 2000; Hodges, 2003). Some people with learning disabilities find it difficult to take the first steps towards adult life and many parents experience difficulty in letting go of their learning disabled adult, son or daughter (Hubert, 1991). The psychodynamic therapy, therefore, can help people to look at the internal-external dimension in their lives, and try to reconcile their inner world with the external reality as other people see it (Sinason & Hollins, 2000).

Regarding the effectiveness of the psychodynamic approach with clients with a learning disability, a variety of studies are in favour of using this approach for this population reporting positive outcomes (Hollins & Evered (1990); Beail (1995); Beail & Warden (1996); Beail (1998); O'Connor (2001); Beail *et al.*(2005)). Since Nadya's presenting problem was her dependency on her family and since there were evidence in favour of therapeutic work with people with learning disabilities using the psychodynamic approach, I was able to make an informed decision about choosing the psychodynamic approach to work with Nadya.

3.6. Summary of the Client's Biographical Details

Nadya was 21 years old, the only child of a divorced couple. Nadya was diagnosed with a mild learning disability by the local Learning Disability Team, she was partially sighted from birth and also had mild mobility problems. At the age of 12 Nadya had a kidney failure and a transplant took place at the age of 20. The time Nadya was attending our sessions her transplant was going very well but she still worried about it.

Nadya's parents divorced when she was three years old. She was born in London to a mixed-race mother and a father of foreign origin. Both Nadya's parents remarried and lived with their partners keeping close contact with each other. Neither couple had any other children. Nadya changed homes during the week since she stayed half the week with her mother and the rest of the week with her father. It seemed as if she was in a constant transition. In both homes, Nadya had her own room and her own stuff and caring arrangements were divided between her parents. Nadya reported feeling confused by having to change homes in the week. She said she would prefer to have a 'stable' home, although she said she liked seeing both her parents during the week. Nadya said her first memory involved her parents arguing and shouting in the living room and herself trying to leave the room by crawling out of it. She did not remember how old she was but she remembered feeling scared about the incident and wanting it to stop.

Nadya attended her final year in college doing a course in child-care. Her father was working in a high profile post at the same organization and Nadya said he was monitoring her frequently. Although Nadya said she enjoyed studying, she did not like her father interfering with her college life - something that he was doing constantly at school and at home with her coursework. Nadya described her relationship with her father as warm and close but said that her father treated her more like a child and was not letting her do things on her own. Nadya gave as an example how her father continued to assist her to change into her nightgown until her current age because he thought that Nadya was not able to do it herself. Nadya felt that her father was not listening to her when she was saying she was capable of taking care of herself in that respect. She also felt that she could understand that her father did those things because he cared for her and felt at times that she could not challenge him because of that. On the other hand, Nadya perceived her mother (a high-profile lawyer) as critical and impatient. She disclosed having frequent arguments with her. Although Nadya admitted that her mother was encouraging her to do new things, she felt that her mother was putting pressure on her to do things a certain way and was not listening to Nadya's explanations when she could not perform the way her mother wanted her to. Nadya said that many times after these arguments her mother would take control and complete things herself without letting

Nadya take on any responsibility. Nadya admitted feeling frustrated, but also very uncertain of what to do. Nadya reported having a neutral relationship with her stepfather picturing him as mostly uninvolved with her issues. However, she said she did not like her stepmother at all because she kept telling her father that Nadya was to blame, when both women had arguments. Nadya reported having a small group of friends from her school and she highlighted her frustration and disappointment about how difficult it was for them to keep in touch with her due to their different schedules. There was no information regarding romantic or sexual relationships in Nadya's history and there were no specific memories mentioned about school or adolescence.

3.7. Initial Formulation of the Problem

Nadya's relationship with her parents was primarily a dependent relationship as there was little acknowledgement on the part of her parents of what she could do for herself. In addition, there did not seem to be much freedom for her to try things out on her own and to experience the results of those efforts. It was my impression that the point of maximum pain (Hinshelwood, 1995) resides in Nadya's early object relationships in which she lived out the experience of being highly dependent, with a mother that was beyond 'good enough' and would not disappoint her so that Nadya could be more autonomous. This dependency was further reinforced by her other disabilities. Nadya's presenting problem was being too dependent and she was seeking my help to become more autonomous. Despite Nadya's request for a more independent object relationship, she displayed ambivalent behaviour around the idea of independence (Nadya's anxiety was probably deriving from this ambivalence). This conflict between independence and dependence was manifested in her need of my hand to enter the counselling room at the beginning of the therapeutic relationship and which stopped as the therapeutic work progressed. This made me wonder: Is Nadya exaggerating her "blindness"? Can she be more independent than she seems despite her disabilities? What should my stance be towards her: respond to her anxiety or allow her time to find the answers herself? Nadya appeared to have learned in her early object relationships that it was through compliance that she received

acknowledgement and approval. Perhaps compliance might have been the defensive relationship pattern that Nadya used instead of challenging her parents. Examples of such compliant behaviour include Nadya allowing herself to be dressed like a child by her father and allowing her mother to do things in her own way for Nadya. This was replicated in the transference relationship in which I vacillated between willing to either offer the client solutions and answers to her problems, or feeling tired at the slowness of the sessions.

3.8. Negotiating a Contract and Therapeutic Aims

I made a verbal contract with Nadya concerning counselling sessions. The Service permits me to see a client on a long term basis without a specific time frame. Although, Nadya and I agreed on leaving the number of sessions open, she expressed her desire to have a specified number of sessions at first because she said she did not know whether she would like the sessions or not. Therefore, we arranged to have ten sessions at first and then revise and see if there is a wish for continuation. I reflected upon Nadya's request and on its impact on the therapeutic relationship regarding the frequent experiencing of small endings (Mander, 2000b). I wondered whether the challenge of the service's open-ended contract reflected Nadya's issue of dependence. By adopting a short-term contract[1], she might have been alleviating any fears of dependency on the therapy and the therapist (Mann, 1973). Having in mind Nadya's previous experience of counselling, I also wondered whether her request was related to her wish to see if I would be either a responsive or unresponsive parent/mother (Winnicott, 1971) - perhaps in the same way she experienced her previous counsellor.

I also explained the boundaries of the counselling session (Jacobs, 1999) in terms of time and frequency –sessions were to be held once a week, for 50 minutes, on a specific day and time - as well as, confidentiality issues. I also had in mind to assess Nadya's level of language and see whether she was able to understand the therapeutic contract (O'Hara & Sperlinger, 1997). Nadya responded positively to the boundaries and fed back to me the meaning of confidentiality showing me that she understood. In terms of therapeutic aims,

Nadya wanted to discuss her choices and to see whether she could move out of her parents' house to a care home or community home. She also wanted to be able to go out and meet people so that she can have friends. Finally, Nadya wanted to talk about her relationship with her parents and see how she can make them listen. I replied to Nadya that we could gradually explore her issues and the emerging feelings, having in mind Mander's view that the psychodynamic psychotherapist "allows the patient ample time to cover all areas and the details of her actual and remembered life which emerge by association in the ongoing dialogue (Mander , 2000a, p. 55).

4. The Development of the Therapy

4.1. The Pattern of Therapy

Nadya attended all arranged sessions, she would come on time and only cancelled once well in advance. We had a gap that was significant for the therapeutic relationship: a three-month gap due to Nadya's moving to a learning disability home and to her later on hospitalization due to kidney problems. After her hospitalization,   Nadya had problems in her new residence that brought up the possibility of terminating her contract. After handling this crisis successfully, Nadya decided to end and we arranged a planned ending.

4.2. The Therapeutic Plan and Main Techniques Used

The initial therapy plan was to build a "therapeutic alliance" so that Nadya could open up to me (Horvath et al., 1993; Papadopoulos, Cross & Bor, 2003) and get to know each other (Simpson & Miller, 2004). I had in mind Bion's perception that the therapist makes an attempt to understand the client, to get to know the client, not by an accumulation of theoretical concepts but by an intimate process of knowing (1962). I tried to do that by listening carefully (Hodges, 2003) and reflecting back Nadya's words and sticking to the

therapeutic boundaries in order to provide a safe and holding environment (Winnicott, 1958, 2002). I also used interpretation in my work with Nadya so as to make a link between what she was describing and what might have been happening between us in the session (Jacobs, 1998) and, would thus, suggest the possibility of unconscious feelings and ideas which she might not be fully aware of (Jacobs, 1999). However, I tried to carefully consider the use of language with Nadya by using common language with her and offer interpretations tentatively. As Hodges (2003) suggests: "people with learning disabilities may need reflections and interpretations to be made in a way that can be understood, with language carefully chosen" (Hodges, 2003 ,p. 55) - so that interpretations are not received concretely (Parsons & Upson, 1986). I also tried to contain Nadya's anxiety and ambivalence at the prospect of moving to her new home and when problems arose during her stay. By not rushing to offer interpretations or suggestions, by reflecting and exploring further Nadya's thoughts and feelings and by enabling her to express herself, I created for her a parental figure that was more accepting, understanding and accommodating than the one of her parents. I aimed to stay with her in the time of transition listening to her ambivalence. Nadya confirmed the accuracy of my intervention by saying that she felt that 'I was listening to her in our sessions' . In addition, by keeping the boundaries and the therapeutic frame firm (e.g. beginning and ending on time, managing interruptions from staff members, keeping the room structure the same every session etc) I provided her with a safe environment to explore feelings and showed her that it is possible to manage anxiety and life events (Chan, 2001). Bion (1962) perceives the therapist as a container that can hold the client's feeling so that she is then able to take them back or introject them already processed and modified. Containment is quite an important concept for people with learning disabilities because it seems that in many cases parents of disabled children find it difficult to manage their own feelings and, thus, to think and contain their children's emotions or projections (Bicknell, 1983; Sinason, 1992; Hodges, 2003).

4.3. Key Content Issues and the Therapeutic Process

Nadya talked extensively about her relationship with her parents. This gave me the opportunity to address what may have been happening between us in the session (Jacobs, 1998) and explore transference issues. For example, I made a link between how Nadya was experiencing her parents and how she was experiencing me. Nadya seemed to experience both parents as not understanding her need to be independent and as not allowing her to do things on her own. In the beginning of our relationship, Nadya projected to me the relationship she had with her parents expecting that I would react in the same way.

When I interpreted this dynamic from her part, Nadya realised, not without pain, the dependency habit she had developed and she was able to assess the level of independence she was capable of and the level of dependence she needed from others. After this intervention Nadya reported becoming more assertive with both parents, asking them to give her more space. Therefore, Nadya seemed to have developed a positive transference towards me since she was seeing me as "the giving and nurturing parent" (Gomez, 1997, 26) that, as she said, "listened, understood and responded to her".

Another major issue for Nadya was moving out of her parents' homes to a home for people with learning disabilities. Although happy, Nadya felt ambivalent at this prospect; on the one hand she was excited but on the other hand she felt afraid. She felt caught between her desire to be independent from her parents and her need to still be taken care of. As Briggs (2002) notes, leaving home, leaving care "splits the young person into one part that is still a child and another that has to be adult"(Briggs, 2002, p. 169) and it seemed that a similar process was taking place inside Nadya.

Another major issue was Nadya's attachment to her parents. Nadya worried about moving on and the impact it would have had on her parents. She realised that she was the link that kept them connected and worried that their relationship would stop when she would not be present. There were two reflections made here: At first I offered an interpretation to Nadya in terms of what it would mean to her if she left her parents'

home and moved on with her life, and what it would mean if she felt she would surpass her parents in order to do that. I also reflected back to Nadya her worry and made a link as well with what her moving on would mean about our relationship – that perhaps Nadya's continuation in therapy could be put into question.

During the therapeutic process I also became aware of the feeling of time passing very slowly in the session. As Hodges (2003) explains, this is a common countertransference response when working with people with learning disabilities. This is because of a higher possibility that very painful feelings and experiences emerge as a reaction to the presence of something that is very difficult to think about. Upon reflection I realized that being with and waiting with Nadya without knowing was unbearable for me. I struggled frequently with the process of not knowing as a trainee and I have addressed this in personal therapy as well.

4.4. Difficulties in the Work

An emerging difficulty in my work with Nadya was her extended absence and her hospitalisation. I was in doubt how I would handle her absence and how long I should wait for her return. I brought these worries to supervision and was advised to allow the client to return when she felt ready since it was felt that she wanted to hold the space open and stable in the middle of all the changes she was experiencing. Additionally, it might have been Nadya's need as well to test our relationship and see whether I could survive this experience with her, leading her to the realization that our relationship is "permanent"; that "whatever happens it will stay secure within the boundaries" (Jacobs, 1998, p.204). I had also to be aware of my countertransferance feelings towards Nadya leaving me (Hodges, 2003). I felt confused being in this situation and having to wait to see how the relationship would evolve - perhaps I felt how Nadya was feeling about her current life events as a result of reactive countertransference (Clarkson, 1995).

Another difficulty in the work was the involvement of Nadya's mother. In the middle of the meeting arrangements, after Nadya's absence, her mother asked me to have an ending with Nadya and to refer her on and share information with a new counsellor. I perceived this as an aspect of a triangular relationship, where Nadya's mother may have found it difficult to understand and accept the type of intimacy between Nadya and me (Jacobs, 1998). Obviously I brought this matter to supervision and I tried to ensure that Nadya had "space, time and separatedness supported by the privacy of our sessions" (Jacobs, 1998,p. 168). I stressed to her mother that the ending of therapy with me would be Nadya's choice and my client would be the one to decide what she wanted to do and speak for herself. Nadya was aware of her mother's view when we met again and she told me that she wished to continue with me until the crisis was over.

4.5. Making Use of Supervision

Supervision played a critical part in my work with Nadya. Being a novice in working with disabled clients, supervision helped me to see other aspects of disability and understand better the relationship dynamics with Nadya. Having a dynamic supervisor has helped me greatly to reflect upon the importance of maintaining clear boundaries with clients with learning disabilities (Kahr, 1997) and upon transference and countertransference (Jacobs, 1999). Transference took place when Nadya projected to me a caring figure (possibly a good part of her ego) (Bott Spillius, 1988), when she used words like 'helpless' and 'I don't know what to do' and I felt an urge to care for her. Being in supervision has helped me monitor my countertransference i.e. my feelings of anxiety in relation to Nadya's helplessness. In addition, I was able to stay with the anxiety, the 'not knowing' and control my impatience about what will happen with Nadya.

4.6. Changes in the Therapeutic Process Over Time

Nadya's identity changed considerably in the process of our therapy. She was able to contain her anxiety and move to her new home and managed to deal with the crisis that emerged after her hospitalization and asked for another chance to stay in the residential setting. Also, Nadya seemed more confident in our sessions and she appeared more of an adult (Briggs, 2002). She would remind herself frequently of having choices as to how she can handle things and she described the relationship with her parents as becoming more equal. Furthermore, Nadya stopped referring to herself as blind. In one of our last sessions she mentioned to me what she said to her mother in the car, while Nadya was giving her directions: "I'm not blind, I'm partially sighted".

5. The Conclusion of the Therapy and the Review

5.1. The Therapeutic Ending

Nadya decided to end after dealing with her crisis at her new residence. She said she wanted to stay out of counselling for a while and see how she could deal with things on her own. With her choice Nadya showed me that an unconscious internalised process was taking place in her; on a more obvious level the therapy has become a joint venture, where Nadya became confident about her own autonomy and separatedness (Jacobs, 1998). We had a planned ending after 10 sessions discussing her change through therapy and evaluating her progress. We also tried to make sense of the experience of ending and explore the emerging feelings (Jacobs, 1999). Nadya felt happy and relieved she was able to go through this process and showed her readiness to take advantage of the new opportunities ahead (Jacobs, 1998).

5.2. Evaluation of the Work

Nadya acknowledged that therapy helped her and that she was able to achieve what she came for: moving out of her parent's home, being more independent and improving her social relationships. I felt that despite the difficulties of the work and the fact that the ending was more rapid than I had anticipated (Jacobs, 1998), therapy with Nadya was successful and we were pacing together in this process. I also felt that the outcome of our therapy was positive because Nadya noted that now she knew what to do if problems arose in the future, demonstrating "a new way of thinking as well as a willingness to seek help and contemplate further therapy as and when the need arises" (Mander, 2000, p. 106).

5.3. What was Learnt about Psychotherapeutic Practice and Theory

Working within a psychodynamic orientation has made me realize the complexity of this approach and the different theoretical dimensions that exist. Furthermore, I found this orientation extremely challenging. Self-reflection and being able to explore transference and countertransference were necessary and difficult tasks. I learned that it was essential to follow the client's discourse, but also to monitor constantly my own process during the session. In addition, this case gave me the opportunity to see how it is to work psychodynamically with a client with learning disability and to reflect upon the similarities and differences of this approach with other client groups.

5.4. Learning from the Case about Yourself as a Therapist

Working with disability has made me aware of my own 'disabled' parts and how to contain them. These included my own anxieties and reservations that stop me from moving on. By working through these parts I was able to realize which aspects of being

with Nadya were more difficult (Hodges, 2003). One of the most difficult aspects was the 'not knowing' position; not knowing what will happen after a change takes place in life.

Through this process, therefore, I learned that therapy may not always finish at the right time for both parties (Jacobs, 1998) and that the therapist's ability to tolerate loss and separation is as important as the client's willingness to separate (Mander, 2000). Working with Nadya has assisted me in working through how it is to end with a client earlier than expected and in dealing with my feelings of sadness when having to say goodbye. As Simpson and Miller (2004) suggest "this work requires the therapist to be receptive to the primitive feelings evoked in herself…requires us to face our limitations and to manage despair" (Simpson and Miller, 2004, p. 132).

Finally, engaging with a client's real potential was a new learning point for me (Simpson & Miller, 2004). Not knowing what Nadya could accomplish was a challenging process since I was facing my own limitations as a therapist. It is very hard to realize that as therapists we sometimes carry expectations of how our clients should evolve and what they should accomplish. My work with Nadya showed me how to put aside my expectations and wait for my client to show me her process.

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Part D: Critical Literature Review

Title: Bereavement Counselling for People with Learning Disabilities: A Critical Literature Review

1. Abstract

This critical literature review aims to explore and present approaches and tools that are employed in bereavement counselling for people with learning disabilities. The review critically evaluates current literature on the approaches that used and their effectiveness. Apart from the assessment of therapeutic tools and approaches, findings regarding the experience of loss of people with learning disabilities are presented in the light of providing insight to the needs of this population. Additionally, this review focuses on gaps in current research and offers recommendations regarding methods and tools to improve clinical practice for counselling psychologists.

2. Bereavement Counselling for People with Learning Disabilities: A Critical Literature Review

3. Introduction

Bereavement and loss are part of human nature. The loss of a loved one is a tragedy not comparable to any other for most bereaved people. Among other challenges, people with learning disabilities frequently have to cope with death and bereavement and usually respond to grief in a very profound way (Read, 1999a, 1999b). Bereavement counselling is often provided to people experiencing grief (Worden, 2001). However, in terms of the learning disability population literature has often shown the struggle of clinicians, including counselling psychologists, to understand how to help this client group when facing bereavement and how to conduct bereavement counselling with this population (Sinason, 1992; Oswin, 1992; Cathcart, 1995; James, 1995; Elliott, 1996; Huline-Dickens, 1996; Read, 1996; Read, Frost, Messenger & Oates, 1999; Read, 1999; Read, 2001; Dowling, Hubert & Hollins, 2003; Gault, 2003; Read & Elliott, 2003; Summers & Witts, 2003, Read, 2004).

Consequently, this literature review aims to review and present approaches and tools that are employed in bereavement counselling for people with learning disabilities. Apart from a focus on therapeutic tools and approaches, findings regarding the experience of grief of this client group as well as what counselling psychologists should be aware of shall be presented in the light of providing insight into the needs of this population. Gaps in the research shall be identified and recommendations regarding methods and tools to improve clinical practice will be made where appropriate.

4. Definitions

4.1. Bereavement

Bereavement, grief and mourning are terms that are used interchangeably in the grieving process. According to Stroebe, Stroebe and Hansson, bereavement is "the objective

situation of having lost someone significant" (Stroebe, Stroebe and Hansson,1993,p. 5). Grief "indicates the experience of one who has lost a loved one to death" (Worden, 2001, 10) and mourning applies to the process that the person undergoes in order to adapt to the loss (Stroebe, Stroebe & Hansson , 1993).

4.2. Learning Disability

There are various definitions for learning disability since it is a term whose meaning has often been debated. O'Hara and Sperlinger (1997) link learning disability to "mental retardation" defining it as a significant below average intellectual functioning appearing before the age of 18 and having limitations in two or more of the following areas: communication, social skills, self-care, living at home, health and safety, hobbies and work, academic skills and use of community resources.

5. Theories of Bereavement

There is a range of theoretical perspectives aiming to explain the experience of bereavement. These include medical theories, psychoanalysis, attachment theory, personal construct theory and cognitive theories and phenomenological/existential approaches to bereavement.

5.1. Medical Theories

Illness and disease theories viewed bereavement as a disease or a syndrome and although grief in itself is not a physical illness, it is supported that it can be linked to the onset of a medical condition (Engel, 1961; Littlewood, 1992). The defining characteristics of a medical condition depend on the extent of grief and can cause pain, disturbance of physical and mental functions, lack of concentration, impairment of memory and in general pathological grief can cause a disruption from normal everyday life and responsibilities (Walsh, 2007). Biological explanations of grief advocated that grief involves the interplay of two opposing response systems: the fight or flight and the conservation-withdrawal system (Irwin et al., 1988; Eisenbruch, 1984; Averill, 1968;

Darwin, 1872; Littlewood, 1992). Agreeing with Walsh (2007), it is noted that, from the medical perspective, grief is perceived as an illness manifesting its symptoms. If bereavement is an illness, it represents an undesirable 'condition' and 'cure' needs to be sought. Terms such as 'resolution' and 'recovery' are used to describe the outcome of bereavement, suggesting the individual overcomes an illness (Payne, 2004). As it will be described below in *Phase Models of Grief*, bereavement models that are influenced by the medical approach are characterised by a developmental framework, in which bereaved people progress through each phase or stage in a coherent and linear manner. The medical approach, although useful, seem to be incomplete to an extent, since it fails to shed some light into the internal psychological processes of grief.

5.2. Psychoanalytic Theory

Influential explanations on grief also stem from the psychoanalytic perspective. Freud studied bereavement in terms of ambivalence and loss: the ambivalence of the lost relationship (Freud, 1917; Pincus, 1976; Rubin, 1984). He believed that the aggressive component of the ambivalent state turned inwards and caused depression. He also perceived grief as a lonely process and did not acknowledge the value of talking and seeking support from others (Blackman, 2003). Freud believed that the ambivalence experienced in grieving is mirrored in the dilemma between the need to relinquish the relationship with the deceased and a wish to maintain the bond with the loved one (Payne, Horn & Relf, 1999).

Freuds' perspective on grief based on psychoanalytic theory was heavily criticised for having no confirmatory evidence (such as in Shackleton, 1984). However, agreeing with Blackman (2003), there can be things that are not measurable and psychoanalytic theory is based upon logical steps, valuable in their own way. Another question upon Freud's theory, as observed also in Klass, Silverman and Nickman (1996), refers to the value of focusing on the task of relinquishing bonds to the deceased in order to smooth the progress of grief and whether this is indeed the purpose of grief.

Despite these arguments, Freud's contribution to this area raised interest and was the foundation upon which other theories of grief were built. Klein, for instance, developed further the theme of pathological grief suggesting that it resembles the manic-depressive state (KIein, 1940). She believed that loss in mourning may be experienced as punishment (Klein, 1948; Littlewood, 1992).

The psychoanalytic approach on grieving triggered a variety of studies on bereavement (such as Lindemann, 1944; Marris (1958), and later on Bowlby (1960, 1963, 1973) and Parkes (1965, 1972, 1975) that produced some interesting insights. Lindemann (1944) concluded that grief was a syndrome with five components (somatic disturbance, preoccupation with the image of the deceased, guilt, hostility and disorganized behaviour). He also acknowledged two patterns of abnormal grief: delayed and distorted grief. Lindemann's contribution, as Blackman (2003) suggested, is essential because he was the first to consider the duration and intensity of grief, the changes in social functioning following grief, as well as, the significance of verbal expression in coping with grief. On the other hand, Marris (1958) proposed that grief is present in a certain quantity, which one has to let go. He also highlighted the significance of funerals. He thought of bereavement as a major life change and its reactions serving as a model for the individual to understand reactions to other important events (i.e. marriage). For Marris (1958), two conflicting states emerged in bereavement: wishing to return to the time before the death and wishing to deny or forget the death. He suggested that recovery followed after this conflict was resolved, otherwise abnormal grief occurred.

5.3. Attachment Theory

Attachment theory also made a significant contribution towards understanding the experience of bereavement (Smith, 1976). Bowlby wrote that parental relationships are the secure base of operation from which to explore and shape a child's capacity to make affectionate bonds later on. A situation like bereavement that jeopardised this bond may fuel intense reactions such as crying, anger and maybe searching for the lost person (Bowlby, 1977). When a person experiences a loss, anger and weeping take place in order for the individual to retrieve the lost object. In that respect, Bowlby concluded that

this desire to recover the deceased represented an instinctive response to the loss of the attachment object that provokes separation anxiety (Bowlby, 1980; Parkes, 1970). Leick and Davidsen-Nielsen (1991) added at this point that when grief is expressed over the loss of a parent, a partner or a child, it may also relate to emotional needs unmet in childhood and which the individual hoped to fulfil by those closest to him/her.

Bowlby's attachment theory made the following important contributions to grief literature. Firstly, he supported that grief reactions were elicited by the loss of an attachment figure. Secondly, the closer and the stronger the attachment, the more powerful and durable the pain of grief was. Thirdly, throughout the process of bereavement interventions, individuals cognitively redefined themselves and their circumstances since this was needed in order to reform internal representations and align them with the emerging changes (Bowlby, 1980; Payne, Horn & Relf, 1999). Bowlby's contribution to the area of bereavement was indeed significant and has influenced subsequent research on this field.

5.4. Personal Construct Theory and Cognitive Approaches

Personal construct theory and cognitive approaches gave another perspective on bereavement. According to Littlewood , "grief involves a person relinquishing their set of assumptions about the world and developing new ones to fit the new circumstances" (Littlewood, 1992, 66). The death of a significant other creates a major shift in one's construct system, but the extent and the nature of change will be determined upon the constructs regarding the relationship between the bereaved person and the deceased (Parkes, 1970; Kelly, 1955, Woodfield & Viney, 1982). Parkes (1988) emphasized the fact that bereavement challenges one's assumptions about the world. According to his view, the bereaved person has to incorporate the changes emerging from the death of the loved one into a new assumptive world.

5.5. Phenomenological and Existential Approaches

Phenomenological and existential approaches suggested that changes in social position, social status and role follow bereavement (Smith, 1976; Towse, 1986). Grief is viewed as

a difficulty "experienced in negotiating a different status and role in the intermediate world of the social network" (Littlewood, 1992, p.73). Additionally, Yalom (2008) viewed grief as an awakening experience that can make one mindful of one's being and place in the world. Agreeing with Yalom's perspective, facing bereavement can evoke an existential crisis, which can demand major decisions and changes to be made in one's life.

6. Normal Grieving

According to Worden (2001) the term 'normal grief' covers a wide range of feelings and behaviours that are common after the death of a loved one. Lindemann (1944) and Worden (2001) observed a large number of bereaved people in a hospital context and concluded that there are four general categories of normal grief behaviours: (1) feelings, (2) physical sensations, (3) cognitions, and (4) behaviours.

Feelings of sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief and numbness are manifested in grief. Sensations like hollowness in the stomach, tightness in the chest or throat, breathlessness, a sense of depersonalization and lack of energy may also be experienced.

Thoughts that are common in the initial stages of mourning encompass disbelief, confusion, preoccupation with the deceased and hallucinations. There are also specific behaviours occurring during the mourning process. Commonly reported ones are sleep and appetite disturbances, absentminded behaviour, social withdrawal, dreams of the deceased, avoidance of reminders of the deceased, searching and calling out, sighing, restless over activity, crying, visiting places or carrying objects that remind the survivor of the lost person and treasuring objects that belonged to the deceased (Worden, 2001).

Wortman and Silver (1989) challenged the traditional concepts of grief and concluded that it was not proven that grief work enabled the bereaved to accept their loss.

7. Phases of Grief and Phase Models

Since the work of Lindemann (1944), several models of grief were developed following a pattern. This pattern could be divided into phases or stages of grief. In order to recover from grief the bereaved individual needed to go through these phases. Literature demonstrated that there are four phases of adult mourning and related feelings that overlap with each other. The first phase is numbness and entails shock and disbelief. The second phase is called yearning and the feelings associated with it are reminiscence, searching of the deceased, hallucination, anger and guilt. The third phase is defined as organization and despair, where feelings of anxiety, loneliness, ambivalence and fear are prominent, and last but not least reorganization is said to be the stage where acceptance and relief take place (Lendrum & Syme, 1992). Shuchter and Zisook (1993) on the other hand integrated the different stage theories of grief and produced three partly overlapping phases: an initial period of shock and denial, a middle acute mourning period of severe somatic and emotional discomfort and social withdrawal, and a closing period of restitution. It is important to mention that these phases may be experienced in different ways by each individual depending on one's uniqueness and personal life history and are not clear-cut, meaning that the bereaved may go backward and forward among them (Raphael, 1984).

7.1. Kubler Ross' Five Stage Model

Kubler Ross (1969) in her work "On death and dying" developed a five-stage model of grief of people who are terminally ill as a response to their illness. She identified five stages: (1) denial and isolation, (2) anger, (3) bargaining, (4) depression, and (5) acceptance.

7.2. Worden's Task Model of Grief

Although there are various theoretical perspectives on grief, a favoured model in bereavement counselling is Worden's tasks of mourning. Literature suggests that this model applies to all client groups including people with learning disabilities (Worden,

2001; Dowling, Hubert & Hollins, 2003). Worden (2001) claims that passing through the process of grief involves going through specific tasks. More specifically, in order to resolve grief the individual has:

- to accept reality of the loss
- to experience the pain of grief
- to adjust to the environment without the loved one making external, internal and spiritual adjustments at the same time, and
- to emotionally relocate the deceased and move on.

It is important to mention that these phases may be experienced differently by each individual depending on one's uniqueness and personal life history and the bereaved may go backward and forward among them (Raphael, 1984).

Agreeing with Read's perspective (2007) on Worden's work, it is essential to acknowledge Worden's contribution to the field. Worden's work not only gave insight about the process of grief, but also highlighted the impending personal challenges emerging when dealing with death. In terms of the practice of bereavement counselling, Worden allowed the practitioner to experience the immensity of this work and stressed the need for frequent support and supervision.

Despite that, several criticisms exist regarding this model. One of them supports that this model's phases are not based on actual empirical studies and have limitations regarding their application to parental bereavement (Rando, 1986; Davies, 2004). Rando (1986) specifically explained the limitations of Worden's model application to parental grief, some of which follow. For instance, the first task of accepting the death of their child was perceived to be difficult because it was against the law of nature: their child should have outlived the parents, not the opposite. The second task was again acknowledged as being difficult because parents grieve not only for their child but also for their lost future. The third task again was identified as difficult for, if there were other children present in the family, parents must continue with parenting and there is no major role of re-definition in this context. The last task was regarded as impossible. As Rando (1986) and Davies

(2004) supported, for the parents their child is an extension of the self and is thus irreplaceable.

7.3. The Multidimentional Model of Grief

Le Poidevin developed a multidimensional model of grief by refining the phases of grief. Her aim was to develop a model that would assist those working with bereaved people to comprehend the individual context of grief within the wider frameworks given by the phase and task approaches. She viewed grief as a process of simultaneous change along seven dimensions of grief. Unfortunately her model remained unpublished. The seven dimensions were the following: emotional, social, physical, lifestyle, practical, spiritual and identity. By describing the main areas of life that are affected by loss, the dimensions of loss enable practitioners to gain an understanding of the individual and their grief reactions. This model assists in the understanding of personal circumstances, the problems bereaved people face and the resources available to assist coping (Payne, Horn & Relf, 1999).

Shuchter and Zisook (1993) also presented a multidimensional model of grief encompassing six dimensions: emotional and cognitive responses; coping with emotional pain; the continuing relationship with the dead spouse; changes in functioning, in relationships and in identity. This model, like the model Le Poidevin suggested, highlighted the individuality of reactions and prevented grief from being viewed as a static or linear process.

7.4. The Dual Process Model

The Process Model created by Stroebe and Schut (1996) constitutes a significant development in the bereavement field. After conducting empirical research, they concluded that avoiding grief can be both helpful and detrimental. Their model's framework was influenced by traditional grief models, but introduced a new idea: an oscillation between coping behaviours. Stroebe and Schut (1996) claimed that there are two prerequisites in adapting to grief: loss restoration (i.e. grief work, being preoccupied

with the loss, ruminating and yearning for the deceased, associated behaviours etc) and restoration orientation (coping, adjustments, distractions from painful thoughts and new identity). They believed that it is important for the bereaved to distance him/herself from the pain of grief because this would assist him/her in creating new roles and relationships and in managing and accepting changes (Payne, Horn & Relf, 1999). The central point to this model is the oscillation between these two states being essential for adjustment. The degree and the emphasis on each approach will be different for each individual (Blackman, 2003). Based on the above, Stroebe and Schut developed four restoration-oriented tasks: firstly, to take time off from the pain of grief; secondly, to master the subjective environment in which the deceased is missing; thirdly, to develop new roles and relationships; and finally, to accept the reality of the changed world (Payne, Horn & Relf, 1999).

7.5. The Biographical Model of Grief

Walter (1996) supported the continuing importance of the relationship with the deceased. He developed a biographical model of grief highlighting the significance of talking to others about the deceased emphasizing the interpersonal, societal context of grief. He supported that conversations with others help the bereaved to create a robust biography that allows them to integrate the relationship into their everyday lives. He insisted that biography construction is best accomplished by talking to others who knew the deceased and not in the context of bereavement counselling. He argued that bereavement counsellors could not engage to the reality testing and that is an important part of creating an accurate biography. He also claimed that working through emotions was not as important as constructing a biography (Walter, 1996). Agreeing with Payne, Horn and Relf (1999), Walter's model has not been empirically tested and is derived from a narrow perspective. Furthermore, this model did not explain how interactions with others provoke change and did not give sufficient explanations for complicated grief and how social networks could enable this to be resolved.

7.6. Sanders' Integrative Theory of Bereavement

Sanders (1999) on the other hand introduced a theory of bereavement integrating various elements of previous grief models. Sanders supported that the individual moves through five phases of bereavement: shock, awareness of loss, conservation-withdrawal, healing and renewal. The central message of the integrative theory of bereavement was that every psychological force that was activated during the process of grief also had a biological predisposition that determined the physical well-being of the individual. Sanders believed that each degree of change and awareness during the grieving process could be viewed as a progression to resolution and homeostasis. She saw bereavement, therefore, as adaptive rather than debilitative, as growth rather than regression. Sanders' model included the notion of motivation in the phases of grief. She also described the bereavement process as free-flowing (with symptoms of one phase overlapping with symptoms of the next phase) and as being characterised by variability in the length of time within which it could be completed.

8. Abnormal Grief

Abnormal or 'atypical grief' or 'complicated mourning' is grief which differs in intensity and duration from the more usual reactions to bereavement (Parkes, 1996). There are losses that generate problems in terms of grieving. 'Disenfranchised grief' belongs to this category. This encompasses losses that are not openly acknowledged, socially supported or publicly mourned (Doka, 1989). This concept recognizes the significance of the social context in which grief is experienced, especially for people with learning disabilities (Read, 1999b; Read, 2007; Read & Elliott, 2007). At first Doka attributed disenfranchised grief to three reasons. These were unrecognized relationships (i.e. extramarital relationships, ex-spouses or lovers, true parents of adopted children, carers or doctors or nurses attached to their patients etc), unrecognized losses (i.e. abortions, loss of a pet, giving up children for adoption etc) and unrecognized grievers (i.e. people with learning disabilities, very young children etc) (Doka, 1989). Later on Doka (2002) identified two more factors: the way people grieve and the circumstances around the death. Grief can be unrecognized if the bereaved person is not capable to communicate or is not anticipated to understand the loss (Parkes, 1996). In this case, people are often excluded from any form of ritual i.e. the funeral. The nature of disenfranchised grief

causes additional issues for the bereaved such as reducing sources of support (Doka, 1989). This is evident in the case of people with learning disabilities since there are few well-organised and available support systems to support them (Read, 2007). Additionally, people with learning disabilities may not be informed about the death or about the funeral and may not be involved in the bereavement rituals for their loved one (Read & Elliott, 2003).

9. Criticisms Regarding Bereavement Models

The above models have proved helpful for practitioners in offering a description of the main themes of grief over time. The main criticism of a phase model of grief is that the complex nature of grief cannot be accounted for in such a simplistic way, by predictable stages and tasks (Maciejewski et al., 2007). Reflecting upon the position of Walsh (2007), most phase models have been criticised as being rigid and prescriptive, suggesting all people go through each phase and in the same order. Although it has always been made clear by theorists that the stages are not a linear process, this may at times be forgotten. Agreeing with Blackman's view (2003), there may still be a risk that phase models could be interpreted too literally, and may be used as a guide as to how people 'should' respond.

Researchers over the years have challenged phase models, defining the grief process as unique and variable for each individual. The grief models described above suggest that there will be an end point to the work of grief. As Blackman (2003) explained, this meant that there would be an adjustment to, or a resolving of, all the issues of bereavement. Some theorists challenged this idea. They stated that mourning is an ongoing process, which may or may not have an ending, and that the timescale is unique to the individual and their circumstances. According to Payne, Horn and Relf (1999), grief may not have a definite end-point which marks recovery. People may adapt to new roles and regain their interest in life and change their relationship to their past but not the past itself, as Silverman (1986) suggested. Resolution, therefore, can continue beyond adaptation to loss and the connection to the deceased can carry on across life, as described by Rubin (1996).

Furthermore, grief models were challenged in terms of the theory of recovery. Researchers, such as Wortman and Silver (1989), suggested that for some people grieving may continue for a number of years without it becoming 'complicated'. Unfortunately, as Blackman (2003) pointed out, there are not enough longitudinal studies of more than two years on the bereavement field, so it is difficult to know how long 'normal' grief should last.

10. Implications of Bereavement Models to the Practice of Counselling

The bereavement models presented previously have several implications to the counselling and the therapeutic support provided by counselling practitioners. These models have informed the clinical practice of professionals, as well as, they have provided guidance and increased our understanding on the process of grief. Additionally, they have made significant contributions to the psychology field. Bereavement models have highlighted the need for further empirical research on the effectiveness of current clinical practices and the development of new ones.

Having bereavement models to guide practicioners' understanding presents both advantages and disadvantages . Bereavement can evoke deep existential issues to professionals working with bereaved people. Having a framework to rely on, can often provide safety to professionals regarding what they should expect and relief from the anxiety of 'not-knowing'. A bereavement model, explaining the tasks needed towards resolution, allows practitioners to develop new approaches, tools and techniques in order to support their clients. However, having a framework to guide clinical practice can be quite prescriptive at the same time, hindering free thinking and (narrowing practitioners' scope), not allowing practitioners to examine other perspectives of the client's experience. Practitioners need to remember to keep an open mind when offering bereavement counselling; each client's grieving process is unique and can vary from what the models describe.

10.1. Implications of Bereavement Models to Counselling People with Learning Disabilities

Bereavement models have several implications to the practice of counselling people with learning disabilities. They have provided practitioners with a framework that could be used with this population, when working with grief and recovery. However, most bereavement models refer to the general population and are not tailored specifically for individuals with learning disabilities. Further research is needed in order to clarify whether the phases of grief and the tasks of grieving apply the same way to the learning disability population.

Furthemore, bereavement models, especially the model about disenfranchised grief (Doka, 1989), have informed counselling practice, in terms of acknowledging the existing complications for people with learning disabilities when grieving. According to the existing literature, individuals with learning disabilities demonstrated significantly increased risk for complicated grief. Evidence confirms a lack of bereavement interventions for this population and a continuing occurrence of unrecognized grief (Emerson, 1977; Strachan. 1981; Hollins & Sinason, 2000; Brickell & Munir, 2008). Based on the theoretical framework of disenfranchised grief, individuals with learning disabilities are much more likely to need professional support in order to cope with grief than the general population. We therefore agree with Hollins and Sinason (2000) that we are to benefit from the contribution of psychotherapy for the treatment of individuals with learning disabilities, who experience loss. Practitioners need to take into account the exclusion people with learning disabilities face from rituals, as well as, the fact that they may need more time to grieve and perhaps would benefit from long-term counselling.

Bereavement models have greatly contributed to the development of bereavement intervention programs. Recent reviews have supported more thorough descriptions of the theoretical models that underpin bereavement-intervention programs (Jordan & Neimeyer, 2003). The use of sound theoretical frameworks has the capacity to identify vulnerabilities in individuals with learning disabilities and consequently to shape treatment programs that can then be further refined through empirical testing (Brickell & Munir, 2008). For example, realizing that individuals with learning disabilities often have

little opportunity to talk about their feelings following a loss, might prompt communication-focused counselling sessions such as those used in the study by Dowling and colleagues (2006).

11. The Bereavement Experience among People with Learning Disabilities

In terms of bereavement, people with learning disabilities are perceived as being "forgotten" and their grieving may not be properly identified or supported (Tuffrey-Wijne, 1997). Only recently has loss been recognized for people with learning disabilities. Waitman and Conboy-Hill (1992) have offered some explanations for this. They noted that death and dying are taboo subjects and it is very difficult to have an open discussion about their meaning and how it feels to lose a significant other. People tend to use euphemisms when they refer to these issues such as 'passed away', 'gone to heaven', or 'gone to sleep' rather than talking directly about the emotional content. Moreover, society's attitudes towards the learning disability client group tend to reject their levels of understanding and their emotional process.

Nagraj and Moddia (1995) claim that a learning disabled person will grieve according to his/her understanding and mode of expression. People with learning disabilities may lack some modes of expression that assist them in communicating feelings but they can show different ways of mourning, taking into account the degree of closeness to the deceased, the extent of dependence and personality traits.

In addition, Moddia and Chung (1995) pointed out that the reaction of this client group may not be apparent at the time of bereavement and it may be difficult to identify it. This population may also undergo changes in their personality, mood and behaviour and may show difficulty in understanding a verbal explanation of the loss (Huline-Dickens, S., 1996). Bihm and Elliott (1982) have argued that the cognitive level of this client group is connected to their conceptions of death. However, Luchterhand and Murphy (1998) believed that learning disabled adults do not have to comprehend the concept of death to feel the loss; they will feel the loss because people are no longer in their lives. Based on her clinical experience, Blackman (2003) explained that people with learning disabilities express their confusion when they grieve through aggressive behaviour and that

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constitutes a normal part of their mourning. Hollins (1995) suggested that searching behaviour and separation anxiety are common after the loss, but angry and aggressive behaviours may be withheld and when they occur, they may not be linked to grief. Summers and Witts (2003) in another case study confirmed the difficulty of people with learning disabilities to convey negative feelings like sadness and anger.

A variety of studies showed that people with learning disabilities exhibit grief responses similar to those of other adults. These include loneliness, anxiety, sadness, depression, behaviour problems, changes in activities, in relationships and personality, exclusion during illness, events surrounding death, participating in the funeral, visiting the cemetery, understanding the death, multiple and gradual losses and getting the right support (Harper and Wadsworth, 1993; Hollins and Esterhuyzen, 1997; Bonell-Pascual et al., 1999; MacHale and Carey, 2002; Dowling, Hubert & Hollins, 2003; Read, Papakosta-Harvey & Bower, 2000; Humlin, 2003; Karavella & Rafalin, 2007). Recently Dodd et al. (2008) revealed that bereaved individuals with learning disabilities experience complicated grief symptoms following the death of a parent, with one-third of the bereaved group experiencing 10 or more clinically apparent symptoms. An interesting point made in this study was that complicated grief symptoms were more likely to occur with higher rates of bereavement ritual involvement.

12. Complicating Factors in the Work with Bereaved Individuals with Learning Disabilities

When working with people with learning disabilities, it is important for counselling psychologists to be aware of existing complicating factors. Literature claims that the cognitive ability of this client group may influence their understanding of death and, therefore, its acceptance (Humlin, 2003). Counselling psychologists should also be aware of potential problems in attention span (Conboy-Hill & Waitman, 1992).

Communication difficulties are another complicating factor. People with learning disabilities may delay expressing their grief or may not have the means to express it

(Humlin, 2003). Sometimes this client group may also have limited verbal skills and poor emotional vocabulary (Conboy-Hill & Waitman, 1992). Prout and Strohmer (1994) suggest that counselling psychologists should provide the client with a language or a way to communicate thoughts and feelings and offer activities to encourage expression. More specifically, counselling psychologists should alter the techniques used by changing the language and making concepts more concrete, and should engage the clients and allow them to express their own voice.

The ability and skills of carers to support these individuals can also facilitate or impede their mourning. People with learning disabilities may be ignored in events before and after the death of their loved ones (Read & Elliott, 2003), especially at the funeral (Raji, Hollins & Drinnan, 2003). The family may react in an overprotective manner and keep the individuals with learning disabilities in distance from the issue of death (Elliott, 1996). However, their involvement may help their grief to be recognized and resolution to be achieved (Hollins, 1995).

Simultaneous losses constitute another complicating factor for people with learning disabilities (Humlin, 2003). This is because the death of their loved one is not the only loss they may face. Change of home, changes of people around them and changes in their everyday routine are additional losses connected to their bereavement. Loss of mobility, loss of functioning and companionship are areas that have to be identified so that the individual can adjust to an environment (James, 1995).

In conclusion, if the bereaved individual lives in residential accommodation, the atmosphere may also change. Staff members may not be adequately trained or they may not feel capable of dealing with the person's loss (Conboy-Hill, 1992; Elliott, 1996). Consequently, this may bring complications in the individual's expression of grief.

13. The Need for Staff Training

It is important to ensure that all staff involved in the care of people with intellectual disabilities possess a good understanding of loss and bereavement so that they are able to

provide effective support before, during and after the death of a loved one (Ryan, Guerin, Dodd & McEvoy, 2011). There were various studies conducted in order to examine the effectiveness of training programmes for staff and carers.

Reynolds, Guerin, McEvoy and Dodd (2008) conducted a study testing the application of a two-day bereavement training program for staff, designed to communicate knowledge and skills that would enable staff to implement practical measures to support people with ID before, during, and following bereavement. The aim of the study was to examine the impact of such a training program on staff members' confidence in supporting individuals undergoing bereavement. The findings suggest that the training significantly increased staff members' confidence in their ability to respond to the challenges of supporting service users during bereavement.

MacHale, McEvoy and Tierne (2009) explored in their study the staff perceptions of service users' conceptualizations of death, reactions to bereavement, required levels of support and the staff's confidence in providing post-bereavement support. Forty-two members of staff rated individuals with intellectual disabilities with whom they worked on a regular basis. In general, staff believed that service users had a good concept of death, though staff tended to overestimate levels of understanding and possibly underestimate the potential for dysfunctional behaviour post-bereavement. Although staff expressed confidence in their ability to recognize grief symptoms, they were less confident in their ability to provide post-bereavement support. The overall picture was positive with a good agreement among staff members, though it became apparent the need for the members of staff to consider the potential for psychopathology following bereavement, as an important factor in providing support. However, this study concluded that the staff needed more input in order to assess service users' levels of understanding and capabilities around death and grief, to be able to recognise dysfunctional behaviours post-bereavement and to be able to monitor changes in behaviour, as well as, to differentiate between normal and abnormal grief.

In a study recently conducted by Watters, McKenzie and Wright (2011), researchers investigated whether a one-day training course improved support staff knowledge about

bereavement and grief in people with a learning disability. A questionnaire based on mixed design was used and forty-eight participants were randomly assigned to one of two equal groups. Results indicated that training significantly improved staff knowledge in all the areas measured.

Although the above studies concluded that staff training programmes were effective in assisting staff to provide adequate support to people with learning disabilities, there was also the recommendation for further training. Perhaps a long-term training programme for staff would be able to cover all gaps and would give staff the opportunity to work on these issues more thoroughly.

14. Bereavement and Loss Assessment Tools

Researching relevant literature in the area of loss, bereavement and psychotherapy revealed several assessment tools that could be useful for practitioners.

14.1. The Six Week Assessment

The Six Week Assessment involves taking an overall view of the bereaved person with learning disabilities that includes the client, the family and the service that has referred the client for bereavement counselling. According to David O'Driscoll (1999), it comprises seven assessment areas:

- Specific loss issues
- Concurrent or multiple losses
- Access to death rituals
- Information given concerning death and how it is understood
- Particular issues of communication
- Particular issues of behaviour or risk
- Ability/will to engage in therapy

The overall assessment is conducted within a six-week period in order for the therapist to gather all relevant information. This long process gives clients the opportunity to

familiarize themselves with the idea of therapy. Furthermore, the counselling psychologist gets a good grasp of the reasons clients are coming to therapy, whether they have difficulty in talking about their bereavement and is able to properly address confidentiality and consent (O' Driscoll, 1999).

Although the six week assessment seems to be a thorough procedure, a couple of factors could be added to the assessment areas so that the process is more complete. These can be the client's age, degree of dependency, emotional closeness to the deceased and capacity to cope with anxiety and stress (Clements, Focht-New, & Faulkner, 2004). Furthermore, research on comparing the effectiveness of the six week assessment and brief assessments (2 weeks) in this client group would be useful in terms of seeing whether this longer method is more effective in assessing clients.

14.2 The Bereavement Needs Assessment Tool (BNAT)

The bereavement needs assessment tool (BNAT) has been developed to help professionals supporting a bereaved person with learning disabilities to make a comprehensive assessment at the point of bereavement (or even pre-bereavement), so that that concurrent losses can be discovered and plans can be put into place as to how to attend to these. The aim of the assessment tool is to clarify the specific bereavement needs of an individual, enabling these to be met. The assessment tool consists of 10 main questions with sub questions. There is a focus on three areas of support: Practical issues, Social issues and Emotional issues (Blackman, 2008).

The effectiveness of this tool is still under investigation since the researcher is waiting for feedback from the professionals that agreed to use it. It would be useful if there were two different versions of the tool developed –one for pre-bereavement, when there is an anticipated death such as terminal cancer and one for post-bereavement.

14.3. Inventory of Complicated Grief for People with Learning Disabilities

Another assessment tool on bereavement suitable for people with learning disabilities is the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID). This tool emerged from the adaptation of The Inventory of Complicated Grief for its use

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with the learning disability population. Carers completed the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID) for a sample of 76 individuals with learning disabilities, half of whom had experienced a parental bereavement within the last 2 years (Guerin, Dodd,Tyrell, McEvoy, Buckley & Hillery, 2009). While the findings suggest that the CGQ-ID is suitable for identifying complicated grief-type symptoms among adults with learning disabilities, further research must be conducted to ascertain whether the findings can be replicated.

15. Therapeutic Approaches for Individuals with Learning Disabilities

My research of the relevant literature has revealed a variety of therapeutic interventions employed for treating individuals with learning disabilities experiencing bereavement.

15.1. Psychodynamic Therapy

Psychodynamic therapy is 'an approach to treatment characterized by thinking about the therapist and the client in a way that includes unconscious conflict, deficits and distortions of intrapsychic structures and internal object relations' (Henry, Strupp, Schact, & Gaston, 1994, 468).

Summers and Witts (2003) in a case study treating a young woman for her father's death highlight several aspects of psychodynamic therapy. They emphasize the importance of helping the client understand what death meant and what actually had happened. This may often involve gentle questioning. The authors also take into consideration the type of attachment the client had with the deceased, as well as, the way the client expresses feelings around the issue. Both authors elaborate on defence mechanisms used by the client when feelings were involved, especially projection[10], and the client's ambivalence. Although this is a small case study, it has good descriptive material and it appears to be

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[10] Projection is a defence mechanism where the person attributes difficult and unacceptable feelings to others, allowing them to let go of responsibility and to feel an imaginary sense of mastery over their feelings (Stroebe, Stroebe & Hanson, 1993).

understandable for clinicians working within the field. Such clinical process can be valuable in understanding further this client group (Counsil Report CR116, 2004).

Additionally, several studies demonstrate the effectiveness of this approach with this client group. Beail and Warden (1996) investigate the effectiveness of psychodynamic psychotherapy with ten adults with learning disabilities undergoing therapy once per week, for a raging period of five to forty-eight sessions. They assessed participants using Symptom Checklist and the Rosenburg Self Esteem Scale and concluded that therapy was effective. Beail (1998) in another study that explored the impact of this approach (short-term) on twenty-five men with learning disabilities and behavioural problems, notes a significant reduction in aggressive behaviour at the end of the treatment. Furthermore, Bichard, Sinason and Usiskin (1996) examine changes in the cognitive and emotional development of eight adults with learning disabilities after having long-term psychoanalytic psychotherapy (three years). Results show that indeed this approach was effective.

Although all these studies support the use of this approach with this population, they did not specifically examine its effectiveness with bereaved participants. A recommendation would be to conduct research on the effectiveness of this approach on bereaved individuals with learning disabilities and see whether there was any difference before and after treatment. The use of a control group, though, in this case should be thoroughly examined for ethics.

15.2. Cognitive Behavioural Therapy (CBT)

CBT is an approach that deals with thoughts, feelings and behaviours. It is used to alter distorted attitudes and problem behaviour by identifying and replacing negative automatic thoughts.

Looking into CBT studies, a schema focused on cognitive work shows to have a long-term effect on people with learning disabilities (Kroese, Dagnan, & Loumidis, 1997; Lindsay, 1999). This approach was also used successfully with a client with mild learning

disability who worried about the death of his parents (Lindsay, Howells, & Pitcaithly, 1993). The client feared that he would not be able to cope without them. Adapting CBT for this client enabled him to manage negative automatic thoughts and become more confident. Furthermore, authors suggest simplifying the approach and the use of role play and role reversal, as a means of eliciting relevant thoughts with this population. Whitehouse, Tudway, Look and Kroese (2006) also support this idea and conclude that CBT groups support flexibility and adaptation of the therapeutic process for this client group. Kroese, Dagnan and Loumidis (1997) write about tackling the clients' cognitive understanding of death and their subsequent emotions and challenging the cognitive frameworks that clients have regarding death. For example, some clients may have a learned helplessness about life and death after such an experience.

Although studies of this approach show its general effectiveness with the learning disability population, no specific studies have been conducted on the CBT treatment of bereavement and this client group. A study with the use of control groups in this area would be valuable in providing more information.

15.3. Family Therapy

Family therapy is a form of psychotherapy during which the interrelationships of family members are examined in group sessions in order to identify and alleviate problems of one or more family members (Houghton Mifflin Company, 2006). This approach has been described by literature as being appropriate to be used with families that have a learning-disabled member, because it promotes change within the family structure that could be helpful and offers problem-solving approaches (Black, 1987; Shulma, 1988; Vetere, 1993, Goldberg, et al, 1995).

Goldberg et al. (1995) recognises two issues as central in the bereavement therapy process: the changed life-cycle patterns of families with a learning-disabled member and the significance of grief and mourning for all family members. Counselling psychologists can work around this process by considering a series of hypotheses in their feedback with

the family. A common family response to loss and death is to protect the member with a learning disability. Counselling psychologists can look at patterns of attachment between the family and the learning disabled member. In addition, they can also focus on how the family addressed past losses and how these enable them to face their current experience of bereavement.

Another aspect of family therapy includes the systemic approach. Blackman (2002) describes the systemic approach to therapy as a combination of bereavement therapy for people with learning disabilities with training and support for staff. Within this framework clients and staff can work on the issue of bereavement so that additional support can be provided to this client group outside the sessions.

The systemic approach was also employed in a case study by Campbell and Bell (2010). The researchers conducted a case study on the psychological assessment, formulation and treatment of a woman with a learning disability who recently experienced the death of her mother using a systemic approach to therapy. The interventions used to assist the woman in the bereavement process took place during eight sessions over a 3 month period. The researcher worked closely with the client's sister and the care team. Three areas of intervention are therefore reported: individual work with the client herself, work with the client's sister and work with the client's care team.

Although literature suggests family therapy as being helpful to people with learning disabilities and their grief, there is not enough empirical research with a substantial number of participants showing that this intervention is significantly effective for this population. Therefore, further research assessing the effectiveness of this approach is advised. Research in establishing a specific protocol within the family therapy framework for treating people with a learning disability facing bereavement would be also another valuable contribution.

15.4. Group Therapy

Group therapy is a form of psychotherapy that involves sessions guided by a therapist and attended by several clients, who confront their personal problems together. The

interaction among clients is considered to be an integral part of the therapeutic process (The American Heritage Dictionaries, 2006). Group interventions seem to be widely used in grief work with people with learning disabilities (Pantlin, 1985; Gravestock & McGauley, 1994; Maliphant & Clutterbuck, 1996; Persaud & Persaud, 1997).

Maliphant and Clutterbuck (1996) conducted bereavement groupwork (11 two-hour sessions) with people with learning disabilities using a humanistic framework with additional behavioural tasks. The therapists acknowledged the members' different levels of ability and used Makaton symbols as well. At the end of each session, self-evaluation sheets in addition to verbal checking were used in order to indicate feelings about the group. Content was presented in the form of games, discussion, pictures, exercises, time lines etc. The facilitators claim that the group was beneficial according to the clients' self-evaluation sheets and that it opened the opportunity for other groups to be established.

Pantlin (1985) and Gravestock and McGauley (1994) conducted groups with eight and nine people with learning disabilities using the analytic approach. On both occasions the group seemed to act as a safe container for communicating and expressing thoughts. Members in both groups brought up a number of losses such as bereavement, loss of family or friends and loss of health. However, both parties reported that verbal interpretations made by the facilitators were not often grasped, although members showed insight into their feelings and the feelings of other members in the group.

Boyden, Freeman and Offen (2009) conducted a bereavement and loss group for people with learning disabilities using the psychodynamic approach to therapy. The group ran for 8 weeks and there were five adults who came to the group. The group helped people to share their feelings and experiences and cope with their bereavement. There was a variety of methods elected to generate discussion and elicit feelings, such as videos and experiential activities. The feedback from the group members was positive and suggested that they found the experience of the group to have helped. Participants enjoyed 'getting out of the house/work' and 'meeting new people' which suggests there was an element of

the group that met a social need. One participant reported that it was difficult to learn what happens when people die, which could suggest that some participants may have had difficulty in discussing such an emotional area. This may also have indicated the importance of the educational component of the group design.

Apart from the above therapeutic approaches, groups can have an educational character. Persaud and Persaud (1997) organized an educational programme in the form of workshops[11] for eight bereaved learning disabled people. In the beginning several warming exercises were introduced to the group such as the 'I feel...' exercise and the listening exercise. During sessions the group addressed the following issues with explanations and discussions around each topic and with the use of videos: loss and things we lose, the mourning processes, the funeral, crematorium and cemetery, cultural aspects of death and dying, wills and feelings of anger. The workshop was evaluated in the last meeting by interviewing each group member individually using a prepared list of questions. Researchers report that the workshop was evaluated by the members as being very successful and that its benefit continued after the end of the workshop with the members making the best of the education they received and using it to overcome their losses.

Although these studies were pioneering in showing how group therapy can address bereavement issues in people with learning disabilities, they were not supported by empirical research. A recommendation for further research could include a longitudinal study with bereavement groups of this population to test the effectiveness of these groups over time. It would also be interesting to conduct further qualitative research by having a group that continues for longer than 11 sessions (six months or a year) and investigate the effects over time. Another observation in terms of literature is that therapy groups involved only members of this client group in bereavement. Although we are aware of the ethical risk and perhaps communication limitations, it might be worthwhile to consider including people with learning disabilities in bereavement groups with people

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[11] The course format involved 10 two-hour workshops on a regular day and time.

without a learning disability in order to see whether both parties could benefit from their contributions.

15.5. Dramatherapy

Dramatherapy has as its main focus the intentional use of healing aspects of drama and theatre as the therapeutic process. It is a method of working and playing that uses action methods to facilitate creativity, imagination, learning, insight and growth (The British Association of Dramatherapists, 2006). In bereavement counselling, this approach aims to:

- Enable individuals to establish a concept of grief,
- Normalize the experience of grief for the client
- Explore the client's relationship with the deceased
- Encourage feelings and enable their 'safe' expression
- Build the client's self-esteem

All these aims are pursued through the use of role playing and fictitious realities (Blackman, 2002).

Additionally, Blackman (2002) emphasizes the importance of assessment and evaluation of therapy work within this approach and considers a variety of theories for this purpose. For the client's assessment Blackman suggests that the counselling psychologist should focus on the client's ability to bond and, more specifically, on:

- The client's concurrent losses
- The client's concept of death
- The stage of grief the client appears to be in
- The client's involvement in the death ceremonies
- The relationship with the deceased
- How the client expresses and understands feelings.

In evaluating therapeutic progress she also proposes that the counselling psychologists should rely on their ongoing observations and assessments throughout therapy, on the client's self-assessment, if possible, and on the communication established with the multi disciplinary team supporting the client. Finally, she proposes a communication book that the client can be responsible for containing any references that the client has made regarding any issues of loss in between sessions. Although Blackman makes a fair point in addressing the issue of getting an overview of the client's progress within and outside the session because these two may differ, confidentiality issues are raised regarding what the client wishes to bring in but also outside the session despite their difficulty in carrying information backwards and forwards. Therefore, the client's consent about this suggestion seems to be vital.

Chesner (1995) on the other hand offers another perspective on assessment by concentrating more on observing and monitoring the client's posture and body language (dress, eye contact, mobility, breathing etc) as well as communication (voice tone, facial expression, non-verbal communication, communicating directly or indirectly) in the sessions. Chesner's approach seems to complement Blackman's on how to assess the client during exercises.

Although both professionals seem to offer insight into the use of dramatherapy, when dealing with bereavement and learning disability, their theoretical suggestions are not accompanied by empirical research. A valuable recommendation would be the development of a quantitative study supporting the assessment and evaluation of bereaved learning disabled clients offered dramatherapy.

15.6. Art Therapy

Art therapy is also employed in exploring bereavement themes with people with learning disabilities (Rees, 1998). Literature recommends this approach for individuals with communication difficulties. The medium of this approach is the use of art. Where themes of loss occur in art, the counselling psychologist uses them to help the bereaved person to

bring them out in open through discussion (Nagraj & Moddia, 1995). In this approach the use of colour is particularly important since literature claims that it is an indicator of the client's feelings. As Rees (1998) claims, an image can have an ultimate strength in holding the emotional content of a personal experience and in not needing any words to accompany it. There is a variety of drawing exercises that can be used to facilitate self-expression, for example blank faces to encourage the expression of feelings, body outlines for physical awareness etc (Read, Frost, Messenger, & Oates, 1999).

French and Kuczaj (1992) organized a two-day workshop focusing on loss and change for seven people with learning disabilities and their keyworkers using the creative medium of art in exercises. As each drawing was presented, it became evident that each participant was responding to feelings directly linked to the loss he/she had experienced. Evaluating the workshop, both therapists concluded that "by using creative media, a record of progress, thoughts and feelings can be made by each person on their own terms" (French and Kuczaj,1992, p. 111).

Although this was a pioneering study on art therapy, bereavement and learning disabilities, it presents certain limitations in terms of generalizing the findings concerning this client group and in terms of investigating the degree of effectiveness of the art therapy approach. Further quantitative or qualitative research on the effect of art therapy in bereavement counselling with an appropriate number of learning disabled participants would provide more insight into this matter. Perhaps measuring the degree of perceived improvement of the client in art therapy could also be a valuable piece of research.

15.7. Music Therapy

Music therapy constitutes a new approach to working on the issue of loss in the learning disability population. Hoyle (2010) explored the effect of music therapy on the issues associated with bereavement in three adults with a learning disability. She employed a nine-week group music therapy protocol designed to educate individuals about death and how to deal with feelings that arise when a loved one dies. The Brief Psychiatric Rating Scale for Developmental Disabilities (BPRS-DD) was administered at weeks 1, 9, and 13

to assess any behavioural changes. Following the series of music therapy sessions, one of the three individuals exhibited a reduced level of negative behaviours and two out of three participants demonstrated improved social skills in the group music therapy.

Although music therapy was deemed to be effective as an approach for addressing loss in the learning disability population, we cannot fail to notice the lack of research studies on its effectiveness. It would be essential to conduct further research on the effectiveness of this approach on a therapeutic as well as on an educational level.

16. Alternative Ways of Working with Individuals with Learning Disabilities

Over the years there has been an increasing need to use alternative ways of working in the bereavement counselling of this population in order to enhance their emotional expression. Read (1999b; 2007), who is one of the few researchers to address this issue, has written extensively about using creative ways of working in the bereavement counselling of people with learning disabilities, suggesting a variety of innovative approaches such as life story work and reminiscence work, among others. Another worthwhile suggestion to take into account is the guided mourning intervention provided by McEnhill(1999).

16.1. Life Story Work

Other therapeutic ways of working with bereaved individuals with learning disabilities include life story work (Read, Frost, Messenger, & Oates, 1999). Life Story Work involves getting a variety of information concerning aspects of a client's life such as personal experiences, feelings, thoughts, life changes, family, relationships, birthdays etc. This method aims to highlight some areas of the client's life and provide some insight into the way in which people with learning disabilities perceive everyday events and experience their environment (Hussain, 1997).

This method consists of a number of subsections named after aspects of the person's life, for example Family, Relationships, Education, Community Home, Activities, Hospitals/Services etc. Each of these can be divided further into categories . There can also be questions in each section to stimulate thinking and memories about one's aspect

of life i.e. relationships. However, the questions posed to the client should be flexible in order to follow his/her interest and not the practitioner's curiosity (Hussain, 1997).

The end product of Life Story Work can be a life event book. Gault (2003) presented the creation of such a book in therapy with this population and highlighted how it assists the individual with learning disabilities to develop a sense of identity. Clute (2010) was also in favour of the use of life story books and talked about their effectiveness in case by case descriptions. However, apart from the life event book, another option would be to create a collection box of items including photographs, objects, drawings, ornaments etc that give a sense of the client's personal history (Hussain, 1997).

There is no specific order when conducting the Life Story Work method. Usually, it is advisable to work in the beginning with the client's present situation and then to go to the past. Initially, it seems important to discuss with the client what is done in Life Story Work and to decide what is appropriate for the client to put in. It is advised that the questions be flexible enough to fit in with the client's verbal ability and to ensure that both closed and open-ended ones are used[12] (Hussain, 1997). In general, the counselling psychologist is advised to involve the client in the process of the work as much as possible and to offer options concerning the format of the work, for example a box or a ring binder where he/she can keep objects and mementos. This two-way approach can enhance the communication and the therapeutic alliance. In the beginning, the counselling psychologist may spend time with the client in order to create the cover of the life story book in a meaningful way for the client, for example by giving it a name or by making a picture or a photograph. The aim of this process is 'to capture the uniqueness of the individual in a way that is recognisable to them' (Read, 1999b, p. 11). There is a variety of ready made packages that can aid practitioners and clients in the creation of a life story book or box, for example the package 'My Story-A celebration of my life' (NABS, 1996).

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[12] This is due to the tendency of people with learning disabilities to respond affirmatively in closed-ended questions (Sigelman, Budd, Spanhel & Schoenrock, 1981a; Sigelman, Budd, Spanhel & Schoenrock, 1981b; Sigelman et al., 1982).

Literature characterizes Life Story Work as particularly effective when working with people with learning disabilities since it gives them a voice and since it makes others aware of their experience (Atkinson & Williams, 1990; Walmsley, 1995). Life Story Work can also be used with clients that are non-verbal; this can be done with the use of Makaton signing and symbols (1996) or with the use of art, music and drama therapy techniques - all offering ways in which the clients can communicate their feelings about their experiences in a non-verbal way.

Life story work is also used to tackle bereavement issues (Read, 1999b). The manner in which Life Story Work is conducted regarding loss can be explained in relation to Worden's bereavement model. As described previously (p.251), Worden supported that grief concerning the death of a loved one entails four tasks of mourning. Life Story Work allows the individual to recognize and accept the loss caused by change. The process itself helps the person to think about how he/she feels about the changes. Furthermore, the work focuses on assisting people in making new choices and friendships within their current environment. In agreement with Hussain (1997), a number of the outcomes of Life Story Work mirror the four tasks of mourning thus enabling clients not only to grieve for the loss, but also to cope with their current circumstances in a positive and creative way.

Although the literature suggests Life Story Work as being helpful to people with learning disabilities and their grief, there is not enough empirical research with a substantial number of participants showing that this intervention is significantly effective for this population. Therefore, further research assessing the effectiveness of this tool is advised.

16.2. Reminiscence Work

Reminiscence work focuses on making sense of the past, the present and future steps of an individual (Stuart, 1997) and it has been used specifically with clients with learning disabilities assisting them to cope with loss, change and other difficult situations based on

the past (Atkinson, 1994). Reminiscence could be combined with Worden's task model of grief (1991; 2001) (previously described in p.228). According to Read:

> *'reminiscence may have a place in all four of Worden's (1991) tasks of grieving, as counsellors try and make more abstract concepts more concrete by relating thoughts, ideas and stories to the client's past and what used to be, to try and establish how things are now in an effort to shape what help and support may be needed in the future' (*Read, 1999b, *13).*

The counselling psychologist can try to connect thoughts, ideas and stories of the client's past (what used to be) to the client's current situation after the bereavement. This aims to identify the appropriate future support the client may need in terms of this experience (Read, 1999b).

Relevant literature suggests reminiscence work to be a powerful tool in bereavement counselling with people with learning disabilities (Van Puyenbroeck & Maes, 2008). In their study, Van Puyenbroeck and Maes (2006) used reminiscence work in a group format and concluded that reminiscence group work may have therapeutic use for ageing people with intellectual disabilities. However, it is essential to bear in mind the issue of recall with this population. People with learning disabilities often have difficulty remembering events when a significant amount of time has elapsed and this may be a barrier in reminiscence work. Recommendations for further research might be to assess the effectiveness of reminiscence work with this client group and to investigate if there is any occurrence of memory (recall) problems getting in the way of this method.

Further research is also needed concerning the therapeutic effectiveness of reminiscence work, since there are few studies in this area involving people with learning disabilities. A potential research study could involve the assessment of reminiscence work used as an individual therapy intervention within a specific number of sessions. This could be compared to a control group provided with a different intervention. In order to measure

effectiveness of reminiscence work, evaluation questionnaires could be given to people with learning disabilities participating in the study.

16.3. The Guided Mourning Intervention

Linda McEnhill(1999) suggested a guided mourning intervention that can be used to address past and present losses in learning disabled clients. This is a behaviourist technique proposing that the person fails to resolve grief because he/she avoids the cues associated with the loss. In this technique, therefore, the individual is encouraged to experience the cues and is offered support through the process. Kitching (1987) illustrated a case study with a guided mourning intervention that successfully helped a woman with a 'mental handicap' to resolve her grief and she suggested a number of principles for this intervention adapted to people with learning disabilities. She suggested that a first step would involve explaining to bereaved clients the normal grief process at an appropriate level and exploring with them the stage at which they may have got stuck. The next step would involve a process of facilitating grief, mainly by encouraging clients to talk about the past and to come across the areas they may be avoiding. During this process linking objects (mementos) and getting the opportunity to say goodbye to the deceased in the sessions (or at the graveside) have been helpful for the client to move on. Finally, Kitching advised designing tailor-made packages to suit the needs of each client.

One of the most attractive aspects of this intervention is that it provides a supportive framework where original responses can arise from the therapeutic relationship. These can range from pragmatic approaches to rituals around the time of death to interventions like the Gestalt 'empty chair' technique, whereby a client is able to express thoughts and feelings towards a person not physically present (in this case the deceased) (McEnhill, 1999). In addition, this method can enable this client group to express their grief at a later time, giving thus the opportunity to grieve to the ones left out of death rituals and even to those who did not know what happened to the deceased (Kitching, 1987; McEnhill, 1999).

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Although the guided mourning intervention seems to be a very useful technique, it should be used sensitively and when trust has been established in the therapeutic relationship. The experience of loss and bereavement can often be painful for many clients and a lot of patience may be required until the client is ready to address this experience. Moreover, there is not enough empirical evidence with a substantial number of participants showing that the outcome of the intervention is significantly helpful. Therefore, further research can shed some light in this area.

17. Therapeutic Tools for Bereavement Counselling with Individuals with Learning Disabilities

A variety of therapeutic tools were recommended for use in bereavement counselling for individuals with learning disabilities. These tools could be used on their own or in conjuction to the alternative ways of working described above.

17.1. Family Trees

Family trees or genograms are used frequently with people with learning disabilities in order to identify people that play an important part in their life (Read, Frost, Messenger, & Oates, 1999). They can be designed by using a large sheet of paper (A3) or an illustrated family tree sheet, for example the one offered in an interactive book by the National Association of Bereavement Services (NABS, 1996).

The family tree can provide the counselling psychologist with information about the client's support network and the people who can actively support the client when therapy ends (Read, Frost, Messenger, & Oates, 1999). The family tree can also portray the family/social context the client is placed in. It can include both living and deceased people. The counselling psychologist is advised to encourage the client to participate in this task and in the process of creating the family tree he/she can also empower the client to talk about the identified people in the tree and their relationship (Read, 1999b).

Similar to the family tree, an eco map or a places tree can be another alternative. Designed the same way as a family tree, a places tree is a tree of familiar places that the client recognizes as significant and important (Read, Frost, Messenger, & Oates, 1999). Sometimes people are linked to places and by completing such a map the client may decide to revisit these places i.e. the family home or the cemetery, or to acknowledge the memory (Read, 1999b).

Although literature suggests family trees as a useful tool in bereavement counselling for people with learning disabilities, not enough empirical research is conducted in terms of how significantly effective it is as an intervention. A recommendation would be to use it in conjunction with a therapeutic approach in order to maximize the outcome, if it is positive, or to use it as a part of the assessment process in order to gain more information about the client's family history.

17.2. Memory Books

Memory books or boxes have a similar use to the life event book. However, they concentrate more on the memories of the deceased. This is done through the use of photographs, sketches, stories or reminiscences of the deceased loved one.

Read (1999b) considers a memory book to be a powerful tool that allows the client to explore their experience of grief and issues around the deceased. She suggests that the memory book can become the focus of counselling as a result of the work. Memory books may be useful for people with learning disabilities in terms of enhancing communication since they combine pictures and text (Hollins & Sireling, 1989; Hollins & Sireling, 1994; Cathcart, 1994; Hollins, Dowling & Blackman, 1995; Stephenson & Linfoot, 1996). Additionally, this tool can be used along as part of a therapeutic approach for bereavement.

Still there is not enough empirical research claiming memory books to be significantly effective in bereavement counselling and more research is needed in order to support their effectiveness.

17.3. Pictorial Books, Videos and Photos

Read, Frost, Messenger and Oates (1999) claim, that pictorial books can be "powerful aids in the exploration, understanding and clarification of death, dying and bereavement' (Read, Frost, Messenger and Oates,1999, p. 102). Sort stories such as *When Mum Died* (Hollins & Sireling, 1994) and *When Dad Died* (Hollins & Sireling, 1989) describe the story of a family losing a key member in a colourful pictorial format. Pictorial books can be used proactively and reactively in bereavement work with learning disabilities by helping the client tell his/her story after the death and by showing in pictures what the client wishes to say (Read, Frost, Messenger, & Oates, 1999; Read, 1999b).

Videos can also have a profound effect on exploring reactions to funerals, rituals and death (Read, 1999b). Examples of such videos include the speakup video '*Coping with Death'*, a narration from people with learning disabilities explaining what the funeral is in a simple way (Speakup Self Advocacy, 1997), and *'When People Die'* (Hollins & Sireling, 1989), a video with illustrations from the book 'When Dad Died' (Hollins & Sireling, 1991) enabling the facilitator to pause at each page and invite discussion.

Photographs can also be used when working with people with learning disabilities and bereavement (Read, 1999b; Everatt & Gale, 2004). These can be photos of the deceased, the family, the funeral, the church, the cemetery etc. Jackson and Jackson (1999) identified several practical suggestions when using photographs with clients. They suggested during bereavement work arranging the photographs in a chain-like manner as in an album, concentrating on the photos when going through the mourning process, presenting photos that will give comfort and remind the client of happy times, and using photos in order to stimulate memories and prompt communication on the client's part.

Furthermore, Aldridge (2007) initiated a different approach by including photographic methods in qualitative research with people with learning disabilities in order to extend our understanding of lived experience. Participants (people with learning disabilities) in this study took photographs of themselves (using disposable cameras) in order to visually illustrate their experiences. The researcher claimed that this approach was particularly effective and allowed participants to express themselves in other ways. Although this study was not focused on the use of photographs as a therapeutic tool for bereavement issues, it offers a novel perspective that could enhance the use of photographs in bereavement counselling. Practitioners could encourage clients to take their own photographs and bring them in the sessions, allowing this way different meanings and new details of their experience to emerge.

Although literature recommends these tools as being helpful in bereavement counselling with people with learning disabilities, it seems that there is the assumption that this client group, after understanding them, will be able to express their emerging feelings. Although studies suggest that combining interventions with pictures and symbols is helpful to the understanding of this population, there is not enough empirical evidence stating that pictures and photos will necessarily aid this client group to express feelings related to the pictures or photos that are displayed. Boyden, Freeman and Offen (2009) held a bereavement and loss group for adults with learning disabilities for eight weeks. During the eight weeks they used videos and picture books among other interventions. They concluded that the group helped people to share their feelings and experiences and to cope with their bereavement, but it was not evident whether the positive evaluation of the group was due to the intervention used. Further research on the use of picture books, videos and photographs with people with learning disabilities and on their efficacy in facilitating emotional expression will be helpful in order to find out whether these means are effective to be used in the bereavement counselling of this population. Perhaps a possible way to accomplish this would be to conduct a study that would focus on the participants' feedback on therapy tools. In this way, researchers would allow people with learning disabilities to identify whether tools such as videos, photographs and pictures were helpful or not to them.

17.4. Poetry

Poetry has been used to encourage people with learning disabilities to express their emotions. From a bereavement perspective, it seems that this method allows the client with learning disabilities to say things which would be difficult to say otherwise and to acquire a better understanding of what is said (Atkinson & Williams, 1990; Shirtliffe, 1995; Read, Frost, Messenger, & Oates, 1999; Read, 1999b; 2007).

According to Smith (1997), it serves several functions:

- It adds an innovative aspect to grief
- Writing can be applied to individuals and groups
- It can assist people in organising what they want to say
- It can help with a shared understanding
- It can be shared with other people like friends and family

When counselling psychologists work around grief with clients, they can help them write poems or texts provided they consider several aspects of this task:

- Explore whether the client has done this before and whether he/she knows what poetry is
- Explore if he/she wants to try
- See if the client can read and write and if he/she wants help when writing it
- Write a poem themselves as well -not only the client (this may encourage the client to write)
- Set a time limit perhaps of 5-10 minutes to write a poem
- Help the client take phrases and write them in a poem format, using rhyming or not. See the poem as a starting point
- Listen to the feelings and to what the client brings in relation to the poem
- Share poems afterwards.

It may also be useful to provide the client with several titles or heading for the poem before writing so that he/she can choose one, if he/she wishes to at this stage (Read, 1999b).

Although literature views poetry and drama as being helpful in bereavement counselling with people with learning disabilities, there is not any empirical research supporting its effectiveness. Recommendations for further research include conducting (a) qualitative studies on the effectiveness of poetry and drama on people with learning disabilities by looking at their experience of these tools in counselling, and (b) quantitative studies in order to measure the number of people with learning disabilities that improved after these interventions.

17.5. The Use and the Creation of Stories

Using and creating stories can serve as a valuable therapeutic tool in the bereavement counselling of people with learning disabilities. For some people, it may be painful to work directly with their own story. According to Bowman (1994), using written material in a therapeutic way can facilitate mourning. Through stories someone can reflect on the process they are experiencing from a distanced perspective. Stories have the potential of unveiling experiences that can mirror elements of one's own life. Through stories, clients are able to acknowledge and take from them whatever they are ready to listen and to understand in relation to themselves. Stories have the advantage that they are connected to change, they can generate questions and develop flexible thinking. One can have the choice to create his/her own story or to use myths and archetypal stories (Blackman, 2003). Gersie's (2003) recommendation for practitioners is to have a number of stories available that are internalized. Such stories can be helpful to use with bereaved clients as a way of bringing up a similar theme to the issue with which they are struggling. As Blackman (2003) explained, the theme of the story does not need necessarily to be about death; sometimes the issue might concern the complexity of relationships, which can relate to the client's relationship with the deceased. Reflecting upon the use of stories in bereavement counselling for people with learning disabilities, we can observe the lack of research studies supporting this tool's effectiveness. Perhaps conducting qualitative research focusing on how stories are used during the process of bereavement counselling of this population from both a therapist's and a client's perspective would definitely enhance this field.

18. General Observations on Alternative Ways of Working and Therapeutic Tools

Reflecting upon the alternative ways of working and alternative therapeutic tools as being described above, it is important to highlight that there is a gap in current literature concerning their use and effectiveness in bereavement counselling for people with learning disabilities. One could think of possible reasons why these research gaps in this field exist. Practitioners may be reluctant to involve themselves in research with the learning disability population and bereavement since both of these topics are challenging. For example, on the one hand, bereavement can evoke one's own losses and can bring up many existential issues. On the other hand, the learning disability population is often considered challenging to work with both in a therapeutic and research context. Many practitioners find therapeutic work with people with learning disabilities slow in pace, repetitive and difficult in terms of communication, not only due to the clients' difficulties to express themselves, but also due to the practitioners' difficulty in really listening to the experience of disability (Hodges, 2003). My previous experience of conducting research in this field - on a postgraduate level (Karavella & Rafalin, 2007) - entailed challenges that could prevent practitioners from conducting research on these issues. One major complication was the difficulty in recruiting participants. This was due to the reluctance of services to advertise the research and to communicate it to potential candidates fearing that the topic of bereavement would be a traumatic experience for people with learning disabilities. An additional challenge involved the development of a sound and rigorous research strategy that would primarily respect and protect participants' rights, and would be capable of giving priority to the welfare of participants over research aims like data collection and research outcomes. Moreover, using people with learning disabilities in qualitative research could be a challenge by itself. It is possible that the researcher will come across communication difficulties when conducting interviews with people with learning disabilities, including difficulties in the reception of the interview questions (understanding and responding to interview questions from the part of the participants). Additionally, participants' accounts could provide less data than the usual amount of data emerging from interviewing other populations. This could potentially affect the process of analysis and the research outcomes. Bearing all these difficulties in mind, it makes sense how conducting research with people with learning disabilities facing bereavement could be daunting. Perhaps

assessing therapeutic bereavement interventions and tools would pose an even bigger challenge for researchers.

19. The Delivery of Bereavement Counselling on a Higher Level

The practice of bereavement counselling for people with learning disabilities draws the attention not only from a therapeutic, but also from a service point of view. Bereavement support does not come only from the counselling room. Organizations play a vital role in the provision of bereavement support. Therefore, there is a need to adopt a more holistic perspective to bereavement support that would include various levels of involvement. Read and Elliott (2007) developed a bereavement support framework that puts forward the holistic perspective.

19. 1. An Integrated Approach to Bereavement Support

Read and Elliott (2007) proposed a bereavement support framework from a holistic perspective for people with intellectual disabilities, which is integrated with a systems approach to care delivery. Read (2005) has postulated a model of bereavement support which involves working at a range of different levels and offers short and long term support, reactive and proactive helping strategies. This model entails four different levels: education, participation, facilitation and intervention. The design of the bereavement support model lends itself to various levels of application within any organizational structure. It can also be applied at a national level to help shape service responses to the needs of bereaved people with learning disabilities. Each component of the bereavement support model can be applied at four levels within systems: Micro level, Meso level, Exo level and Macro level.

The Bereavement Support Framework seems to be a step forward in the area of bereavement and learning disabilities because of the holistic perspective it employs.. According to Read and Elliott (2007), the benefits of this model include empowering both bereaved people and their carers, facilitating coping via a proactive and reactive perspective, reducing the development of pathological grief and the need for specific psychological or psychiatric interventions. It would, therefore, be interesting to see this model developing further and being applied to organisations. Perhaps it would be

beneficial to conduct a longitudinal study assessing the application and the use of this model on micro, meso, exo and macro levels. This could take the form of a pilot study involving one or two services and their service users. Support, training and supervision could be available throughout this program in order to support individuals and services to reach the benefits as being described, but also in order to identify problems and hurdles within the process.

20. Key Messages for Practitioners

Reflecting upon the different therapeutic methods used in bereavement counselling for people with learning disabilities, we can identify several key principles for practitioners.

Practitioners should be encouraged to work creatively with people with learning disabilities. As it has been argued above, working creatively can promote emotional exploration and expression (supported in Read, 1999b, 2007) in the bereavement counselling of this population. Working creatively may involve using alternative ways of therapy, such as the ones described previously. For instance, literature has demonstrated that life stories with the use of mementoes can be particularly helpful to people with learning disabilities in bringing back memories about the deceased. The therapeutic use of mementoes, such as books and photographs, strengthens the mourner's 'continuing bond' with the deceased. Maintaining a healthy long-term bond with the deceased is considered to be important in the successful resolution of grief (Klass et al., 1996).

Working creatively may also entail adapting existing techniques to the needs of the people with learning disabilities. For example, Strohmer and Prout (1994) recommended the following: 1) To alter techniques and tools that are applied to non-learning disabled clients of the same age-group, and 2) to use techniques that are appropriate in counselling with children and adolescents, which means, they are suitable for their age and address them in a socially appropriate manner.

In order for practitioners to be encouraged to offer such interventions, they will have to be educated about the benefits of the alternative strategies for this specific bereaved population (Gilrane-McGarry & Taggart, 2007). In addition to further training, practitioners need to be open to develop their own ways of working and perhaps create their own tools to use in the bereavement counselling of this population. Since there is a lack of current literature upon creative ways of working, practitioners should be encouraged to conduct further research upon this field to enhance their clinical practice.

Furthermore, practitioners need to tailor their intervention to their client's needs and profile and to choose therapeutic tools in a cautious and appropriate manner. Not all therapeutic tools are appropriate for all clients and practitioners need to be flexible in their approach. For instance, practitioners need to be very careful when choosing to use memory books or create life story books during the process of bereavement counselling with people with learning disabilities. A book may not necessarily be the right creative tool for everyone. Some people may have had unpleasant experiences with reading and writing during their school life (as explained in Blackman, 2003). For others, life story books or memory books may not be appealing. Another example is the use of reminiscence work. For some clients, it may be essential for their psychological survival not to remember the past (Blackman, 2003), i.e. someone that has experienced trauma. In this case, practitioners should not force them to remember but instead they will have to find different ways to work with them .

Furthermore, practitioners need to maintain a sensitive attitude to this population's grief experience during bereavement counselling. Talking and reminiscing about the deceased can be extremely painful. As Blackman (2003) suggested, many people have dissociated from painful experiences in their lives by not thinking about them, and this needs to be taken into consideration when beginning counselling and when attempts to re-connect with the past are made during the therapeutic process. It is, therefore, essential for practitioners to establish consent and negotiate ground rules with their client. For example, a possible ground rule could be that the individual can speak only if they wish to.

In conclusion, we need to emphasise the significance of regular clinical supervision for practitioners who provide bereavement counselling to people with learning disabilities. Listening to someone's painful experiences is certainly a difficult process and can frequently evoke practitioners' own losses. Practitioners need to be able to bracket their own experiences and seek support into how to keep themselves from interfering with the client's process. Apart from clinical supervision, support might come in a range of formats (as suggested by Read (1996b, 2003) and Gilrane-McGarry and Taggart (2007)): informal support groups in the clinical area; facilitated critical incident analysis; clinical debriefing; specialist support; peer support; and access to personal professional counselling and voluntary bereavement organisations if necessary. Additionally, Read (2007) suggested shadowing as a useful learning tool for inexperienced counsellors working with people with learning disabilities. Shadowing is usually offered during the assessment period and involves two practitioners working together.

21. Summary

This literature review attempted to explore how bereavement counselling is conducted with people with learning disabilities and to present the application of bereavement theories to this population and the existing therapeutic tools and interventions. Literature shows that it is only recently that loss has been recognized in people with learning disabilities. Reflecting upon various studies in the area, we also come across various complicating factors when treating this client group in areas such as cognition and communication. Relevant literature demonstrates various therapeutic approaches used in bereavement counselling with this population. Among others, psychodynamic therapy, cognitive behavioural therapy and group therapy are considered to be effective . Alternative ways of therapy include the guided mourning intervention, life story work and reminiscence work, while other tools such as memory books and poetry, to name a few, can be of significant help in the counselling process. Although these interventions are innovative, their effectiveness is not supported with enough empirical research and this raises the need to conduct further evaluations.

22. Implications for Practice for Counselling Psychologists

This critical literature review can provide Counselling Psychologists with an understanding of the experience of loss and bereavement for individuals with learning disabilities and with knowledge of how to support this client group. Practitioners may take into consideration these suggestions when they provide individual or group therapy to this population or when they provide support to their carers (Cathcart, 1995; Humlin, 2003).

Moreover, this review could be used as part of training for Counselling Psychologists around loss and learning disabilities. Dryden (1994) highlights the importance of exploring educationally how we could modify counselling training to make counselling accessible to all clients and, therefore, some of the suggestions as they have been presented in this review may be used for this purpose. Additionally, Gilrane-McGarry and Taggart (2007) identified the need for more secondary interventions in the form of bereavement counselling services for the learning disability population. They emphasised the fact that the benefits received from such services need to be integrated into the person's day-to-day life through the provision of supportive informal counselling by front-line staff. This suggests a new area of work opening for Counselling Psychologists, in community residential services and supported living for the learning disability population, making the need for specialized training even more urgent.

23. Conclusion

Reflecting upon the literature on bereavement counselling and learning disability, we come to realize how significant it is to acknowledge the grieving process of these individuals and to give them the opportunity to voice their experience. Clinicians should be aware of the complications that this client group brings to therapy, as well as, how to

deal with them. One of the most important realisations of this review is that further research is needed to address the effectiveness of the suggested interventions for this client group. Continuous training on therapeutic interventions around bereavement and learning disabilities seems to be essential for clinicians in order to ensure a better quality of services to this population. In conclusion, keeping an open mind and treating this client group with respect, equality and empathy are key issues that have also emerged from the research studies and perhaps these are the first conditions that clinicians should consider even before applying therapeutic interventions.

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Appendices

Appendix 1: Sample of Reflexive Diary

<u>Sample of Reflexive Diary</u>

27/04/10

I had the following realization: I manipulated the data. I analyzed the data by organising my participants' experience with my own way. I did not stay close to the data experientially but I followed that cognitively. I misconstrued parts of the analysis by imposing my own assumptions. I have to re-do the analysis. Will this be a new beginning? I also assumed my interviews would give less data due to participants' short quotes. I was very attached to the idea of IPA and cognition. Should I go back to my epistemological stance? Perhaps my writing was so descriptive because my analysis was so descriptive. I did not pull adequate links between the themes. Why is it so hard for me to pull links? Does it have to do with my emotions? How much do I block my emotions and stay with the structure and the cognitive? What am I afraid of seeing? Intense pain, loss, moving and saying goodbye to my independence or even feeling sad about staying in foreign country on my own? It is painful. How much did I block my feelings of loss in order to adjust? Do my participants do the same? Do they lack emotional depth in order to protect themselves? Is this important so that they can survive after the move?

28/04/10

Are participants perceive their ID in a fragmented way? Is it disjointed? Or too emotional?

02/05/10

I have identified so much with the material from the interviews that it is hard for me to make connections across the material. I'm going back to my own moves and the transition to Athens.

06/05/10

I feel frustrated. I think I lack motivation. I feel bored with the material. I have negative thoughts that I cannot do this. It feels like hard labour. I wish someone would do this for me. It feels very hard. I don't know if there is a point in all this. I have so little time to think. I feel confused.

Appendix 2: Validity: Sample of Researchers' Comments

Comments regarding analysis of research – Margarita Karavella

Reading through the themes and quotes, I was struck by the level of detail and the challenge of interviewing participants in this particular population. It seems to require significant probing and encouraging in order to assist the participants to reflect on their experiences and articulate their thoughts and feelings. In certain themes such as the theme of identity, the quotes and theme structure brings to light a very detailed and broken down concept of identity – looking at the particular examples the participants could come up with, and seeing it through their capacity (such as hobbies, activities and daily routine…). Overall, I can follow and agree with Margarita's analysis generally.

Dr E. Murray, Chartered Health Psychologist

Think about incorporating Loss as a subtheme under emotions perhaps-it seemed significant from the transcripts I went through…Very emotional interviews.

Dr Rajvinder Singh Gill, Consultant Educational Psychologist

Appendix 3: Advertising Research Leaflet

Have you changed home?

This project is carried out as part of a Dpsych in Counselling Psychology at City University and is supervised by Dr Deborah Rafalin. Contact details:

Margarita Karavella
07906419686
M.Karavella@city.ac.uk

Dr Deborah Rafalin
020 7040 0167,
d.rafalin@city.ac.uk
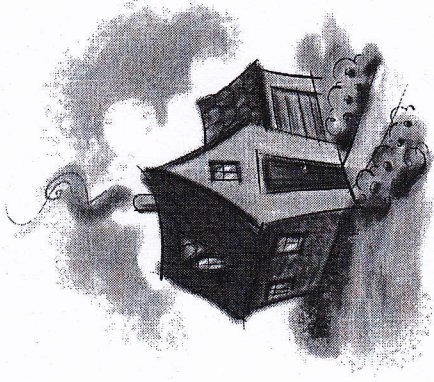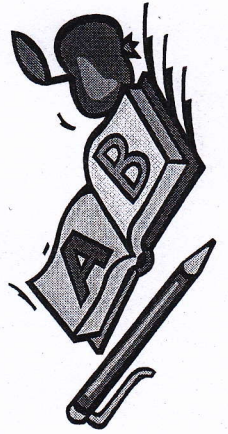
My name is **Margarita**

I am training to be a psychologist

I would like to talk to you about how you felt when you changed home.
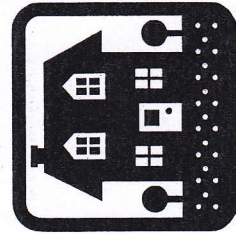
This will be a part of my project.
By sharing your story you can help me teach others about how you coped

It will take about 1 hour of your time and I will come and meet you
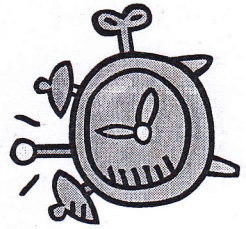
If you are interested or want to chat to me please call me on
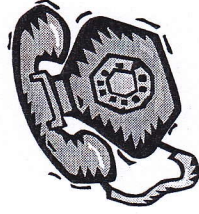
07906419686

or

give this pamphlet to your carer or parent to help you. They might like to speak to me too

Appendix 4: Participant Summaries

The following summaries are small informal descriptions of the participants in this study that are not based on the demographic information given in the Methodology section. These summaries constitute my memory of participants from our discussions. My aim is for you to see them through my eyes.

Mary is a 65-year old lady who is bounded in a wheelchair from a young age. Judith enjoys going to church. She is pleasant, soft-spoken, gentle and enjoys working with children on Sunday's church.

Angela is a 42-year old lady who comes across as younger than her age. She is energetic and expresses her views intensely and talks constantly. Angela is very anxious and expresses that clearly in the way she talks. She misses her family terribly and especially her mother and longs to be closer to her. She is very proud about her family and makes plans for trips to visit them. She can come across as demanding and someone who complains a lot.

Philip is a 48-year old man living in a carehome with his own room. Philip is very shy and timid and he speaks in a very low voice. He is polite and likes travelling. He finds it difficult to express himself and needs a lot of prompting.

Josephine is a 60-year old woman. She is pleasant and polite. She talks a lot a about her feelings. She likes fine things and she takes good care of her appearance and herself in general.

Lee is a 26-year old young man. He is friendly and pleasant to talk to and seems very shy. He likes being in the care home because he feels he has gained independence from his mother. He enjoys being part of a team and learning new things. He has a strong relationship with his keyworker and relies a lot on him.

Redhead is 45. He is very independent, optimistic and has a good sense of humour. He takes initiative often and has conducted a survey for the rights of disabled people. Redhead has being a victim of abuse by his family. It seems that through this experience Redhead survived, became stronger and managed to be an assertive individual, sociable and pleasant. Redhead had been married to his wife, who passed away a few months ago. He misses her terribly.

George is 58-year old Irish man. George likes smoking and drinking tea and going to the Pub down the road. George has fixed routines in the care home. He is has false teeth but does not wear them and as a result his speech is many times incomprehensibleHe left from his previous home because he was not wanted and he seems to have experienced his move as very traumatic and as an emergency.

Ching Dynasty is a 25-year old young man. Ching Dynasty is a confident and very attractive young man with a good sense of humour. He is very independent and he is the front face of the charity he is working. His optimism has helped him evolve and inspire his fellow residents. Ching Dynasty has recently got married and is very much in love with his Japanese wife. He talks about his responsibilities and how he takes care of his wife. His wife seems to be the center of his life. He looks forward to become a father.

Alf is 44 years old. He is very shy and takes a long time to reply to questions. Alf thought that the move was a big deal to him as a process. He seems to feel safe with maintaining his routines.

Tim is 35. He mostly repeats my last words. He likes collecting pens from others and he is afraid of the dog that lives across the care home, who often barks.

William is 57. His speaks in a strong northern accent. He finds food important in the care home. He liked his previous home better because the space and the furniture were bigger.

Charlie is 52 and Jewish. He likes travelling to places as well as playing football. He likes telling jokes and meeting people. He is very sensitive with too many questions and does not like talking about negative things or experiences.

Jasmine is 46. She takes pride in her room and how tidy it is. Jasmine talks about her anger towards people and how the moves were traumatic for her. She feels many things were not her choice. She felt angry she moved home.

Rose is a fan of Dr Who and likes going top his conventions. She describes herself as very independent. She expresses well herself verbally, she is sociable, polite and makes good conversation.

Appendix 5a: Ethical Approval

Ethics Release Form for Psychology Research Projects

All students planning to undertake any research activity in the Department of Psychology are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department of Psychology does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2004) <u>Guidelines for minimum standards of ethical approval in psychological research</u> (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by 2 members of Department of Psychology staff.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc ☐   M.Phil ☐   M.Sc ☐   Ph.D ☐   D.Psych ☑   n/a ☐

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

The impact of change of home on the identity of people with learning disabilities

2. Name of student researcher (please include contact address and telephone number)

MARGARITA KARAVELLA, R490B, WALTER SICKERT HALL, 29 GRAHAM STREET, LONDON, N1 8LA, 020 7040 7650, 07906 41 96 86

3. Name of research supervisor

DR DEBORAH RAFALIN

4. Is a research proposal appended to this ethics release form?   (Yes)   **No**

5. Does the research involve the use of human subjects/participants?   (Yes)   No

If yes, a. Approximately how many are planned to be involved? ---- 10 ish ----

b. How will you recruit them? From the general public, from care homes, housing organisations with the use of flyers

c. What are your recruitment criteria? ---- See proposal ----
(*Please append your recruitment material/advertisement/flyer*) Appendix E

d. Will the research involve the participation of ~~minors (under 16 years of age)~~ or those unable to give informed consent?

(Yes)   No   Possibly.

e. If yes, will signed parental/carer consent be obtained?   (Yes)   **No**

if the participant wishes to

See proposal

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

1 hour of their time, to participate in an interview

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes   (**No**)

If yes, a. Please detail the possible harm? ---

b. How can this be justified? ---

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

(**Yes**)   **No**

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)   Appendix A

9. Will any person's treatment/care be in any way compromised if they choose not to participate in the research?

Yes   (**No**)

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

(**Yes**)   **No**

(Please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)   Appendices B + C

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Tape recordings of interviews, interview transcripts in electronic form, research notes

12. What provision will there be for the safe-keeping of these records? They will be kept in a lock and key cabinet, in computer with a password and identifiable information will be coded

13. What will happen to the records at the end of the project? I will destroy the tapes and all participant records after the appropriate time

14. How will you protect the anonymity of the subjects/participants? I will ask participants to choose their own name for the transcripts and I will use that name in all records. In research all identifyable information will not be used

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

I will provide participants with a resource & list flyer naming possible support options and I will provide debriefing during the research findings and after the study

(Please append any de-brief information sheets or resource lists detailing possible support options)

completion   Appendix F   2

If you have circled an item in bold print, please provide further explanation here:

5. Yes = people with learning disabilities (adults)

Signature of student researcher ------*signature*------------------------ Date --21|7|6--

Section B: To be completed by the research supervisor

Please mark the appropriate box below:

Ethical approval granted ☑

Refer to the Department of Psychology Research Committee ☑

Refer to the University Senate Research Committee ☐

Signature --*DK signature*-- Date--21|7|6--

Section C: To be completed by the 2ⁿᵈ Department of Psychology staff member *(Please read this ethics release form fully and pay particular attention to any answers on the form where bold items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above ☑

Signature ------*signature*------------------------ Date ----28/7/06,

Appendix 5b: Research Proposal

The impact of change on the identity of people with learning disabilities

DPsych Proposal

Margarita Karavella

Top-Up Doctorate In Counselling Psychology

City University, London

Abstract

This research study aims to investigate the impact of change on the identity of people with learning disabilities. More specifically, how change from one context to another (e.g. from family home to carehome) can influence the identity of a person with learning disabilities.Gaps in the existing literature indicate that there is still enough space for research to take place on the quality of the experience of this client group. Ten learning disabled adults will be recruited as participants from the general public. They should be over 18 years of age, consider themselves as having a learning disability and have had direct contact with learning disability services in the past, have experienced a change of context at some period in their lives, and be able to verbally express themselves. Individual semi-structured interviews will be conducted and data will be recorded and transcribed verbatim. Grounded theory will be used as a method of analysis.

Introduction

Loss is part of human nature. The loss of a loved one is a tragedy not comparable to any other for most bereaved people. It is an experience that occurs at some time in nearly everyone's life and brings great emotional pain and grief. Among others, people with learning disabilities frequently have to cope with loss and usually respond to loss in a very profound way.

Rationale for the Work

Working with bereavement, as a trainee counselling psychologist, has shown me the uniqueness of the experience of loss. In addition, working with people with learning disabilities has increased my understanding of their needs. I was inspired by this experience in my training to pursue a further understanding of how this client group experiences bereavement. Exploring this topic in my MSc thesis, raised a variety of questions and prepared the ground for further research.

People with learning disabilities often face simultaneous losses (Humlin, 2003). This is because the death of their loved one is not the only loss they may experience. The death may bring many different changes. Change of home, changes of people around them and changes in their everyday routine are additional losses connected to their bereavement. Loss of mobility, loss of functioning and companionship are areas that have to be identified so that the individual can adjust to an environment (James, 1995).

Reflecting on my MSc analysis, a prominent theme in my participants was the issue of change after the death of their loved ones. Participants talked extensively about changes in their personality, in their relationships and in their everyday living and functioning. Naturally, the concept of change brought in mind thoughts about how changing context can shape the identity of an individual with learning disabilities and how the self-concept of this client group is moulded after such an event.

There is a potential research question that I would be eager to investigate at this point: what is the impact of change (e.g. change of home) on the identity of people with learning disabilities. More specifically, how change from a family home to a care home can influence the identity of a person with learning disabilities.

Literature Review

Definitions

Before exploring the impact of change on the identity of people with learning disabilities, it is pivotal to look into definitions regarding these concepts.

The concept of identity is very difficult to define (Beart, Hardy & Buchan, 2005). Deaux (1992) defines identity by contrasting it with the concept of self, which is linked to social roles and personal internal and external characteristics. Hurrelmann (1988) emphasizes the continuity of self-experience in identity, which he defined as having a continued sense of who we are across a lifetime of social roles and biological changes. Other writers emphasize the importance of social identity (Craib, 1998; Burkitt, 1991; Mead, 1934). However, there has been remarkably little research on the impact of being categorized as a person having learning disabilities. As Beart, Hardy and Buchan (2005) explain: "while entire services are set up around this categorization we have little information on the impact of this social identity on people and how it informs and shapes their sense of self"(p.48).

There are various definitions for learning disability since it is a term whose meaning has often been debated. Anna Chesner (1995) notes that people lack awareness in the issue of learning disability and confuse it with mental illness. This attitude may be responsible for the marginalization of this group and for its place in society (i.e. where people with learning disabilities should live). Sinason (1992) links learning disability with the term mental handicap which refers to the emotional and social consequences of one's mental impairment. At the same time, O'Hara and Sperlinger (1997) connect learning disability with "mental retardation" defining it as a significant below average intellectual functioning appearing before the age of 18 and having limitations in two or more of the following areas: communication, social skills, self-care, living at home, health and safety, hobbies and work, academic skills and use of community resources. Emerson (1995) attaches to this definition that a person with severe learning disability manifests: an additional physical or sensory handicap, impairment in the central nervous system, exhibiting signs of major disabilities in acquiring adaptive behaviours from early on implying that they need more support to function, and have a low score (below 50) on standardized IQ tests. Thomas and Woods (2003) report that there are five categories

reflecting the degree of learning disability: borderline, mild, moderate, severe and profound and that the causes of learning disability may result from genetic disorders, cranial impairment, chromosomal anomalies, congenital, psychosocial and environmental factors.

Research on change, identity and learning disabilities

Numerous studies addressed labelling and learning disability (Davies & Jenkins, 1997; Finlay & Lyons, 1998) and some linked it to the identity and self concept of this client group (Jahoda et al., 1988; Rapley et al., 1998). Some have also investigated the identity conflict in people with intellectual disabilities and the role of services (Craig et al., 2002; Thompson, Ryrie & Wright, 2004) but no reference has been made to the change from the family environment to the residential setting and its impact to this client group.

Researching the literature has so far identified one study that discusses change of one environment to the other. This study addressed the deinstitutionalization and rehabilitation of 11 people with severe learning disabilities from a psychiatric institution at Leros island in Greece to a community home in Athens (Tsiantis et al., 1995). It also discusses how the resident care and adaptive behaviour has started to improve and how the communication between the residents and their families has increased. However, no information was given around the impact of this setting change on the identity of these people.

Read, Papakosta-Harvey and Bower (2000) have also touched to an extent the issue of loss, identity and learning disability. They organized a workshop experience for eight learning disabled people in order to pinpoint and explore issues around loss. Evaluation questions were asked in a group setup over six group sessions and the emerging themes regarding loss were loss of self, confusion, frustration of not being able to understand or not being able to express emotions and loss over important life decisions. Group members described having both physical symptoms and psychological reactions. This study increased the possibility of learning disabled people's voice to be heard regarding their experience of loss and its influence on the self even though it addressed the issue of loss and change in a broader sense. In a second study with the use

of workshops, Read and Papakosta-Harvey (2004) used ten people with learning disabilities to explore again in a group context for six sessions loss and change. The emerging themes were collectively categorized as physical, emotional, cognitive and behavioural reactions to loss. This study was a replication of the previous one, but made a step further with the use of storytelling and narrative analysis as part of the analysis of data.

Although continuing literature search is still needed for this research, so far I could identify gaps in research regarding the impact of change of home to the self concept of people with learning disabilities. I feel, therefore, that there is still space for their voice to be heard and for the quality of their experience to be brought forward.

Implications for Counselling Psychology

Bearing in mind that there is limited literature on the topic of change and the identity for people with learning disabilities, I feel that this research can offer insight to the huge topic of identity and learning disability and can present implications for practice for Counselling Psychologists. Through this research, therefore, Counselling Psychologists can gain an understanding of the identity changes for individuals with leaning disabilities. More specifically, practitioners may have it in mind when they provide individual or group therapy to people with learning disabilities. This research may also be used as a part of training for Counselling Psychologists around this particular issue.

Research Aims

The overall aim of this research is to investigate the impact of change on the identity of people with learning disabilities. That is, how change from a family home to a care home can influence the identity of a person with learning disabilities. More specifically:

- To identify what is understood by change of context e.g. home
- To explore feelings and emotions that are often associated with this change
- To explore the experience of change from family home to a care home
- To discuss change of home from a personal perspective

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- To identify changes in self-concept/ personality, if any, after the change of home

- To discuss how one perceives his/her social identity after this change

- To identify coping mechanisms or personal support mechanisms that might have been developed with this experience.

Method

Participants and Recruitment

My intention for this study is to recruit a minimum of ten adults with learning disabilities. The number of participants was decided upon in consideration of the size of the data set that would emerge from the interviews with regards to published research guidelines (Turpin et al., 1997). In order to recruit participants, I have created a leaflet for individuals with learning disabilities aiming to advertise this research. The leaflet is written in language and a format that people with learning disabilities are able to understand (O'Hara & Sperlinger, 1997) and its design is based on books and texts written specifically for people with learning disabilities (Hollins & Sireling, (1989); Hollins & Sireling, (1994); Cathcart, (1994); Hollins, Dowling & Blackman, (1995)). For example, a combination of pictures and text is used to enhance understanding.

The advertising leaflet can be sent to organizations and services for people with learning disabilities, social clubs for this client group, carers' organizations, general counselling services and care homes as well as umbrella organizations.

The necessary criteria for participation in this research would be to: (a) be over 18 years of age, (b) consider oneself as having a learning disability and having had direct contact with learning disability services or a specialist in the past (this would imply a degree of impairment), (c) have experienced a change of context at some period in their lives[13], and (d) be able to verbally express oneself. Needless to say that these criteria need

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[13] This criterion needs further exploration in terms of how long ago the individuals have changed from family home to care home. Further information can be sought by looking into relevant literature.

to be thought through and need further elaboration taking into account relevant literature and other emerging issues in the research process.

Ethics

Since this study will involve adults with learning disabilities, the British Psychological Society Code of Ethics (1997) regarding research should be considered. Informed consent for participants with learning disabilities is an issue that requires special attention. According to the principles of consent of BPS (1997):

> Research with participants who have impairments that will limit understanding and/or communication such that they are unable to give their real consent requires special safe-guarding procedures.

> Where possible, the real consent of adults with impairments in understanding or communication should be obtained.

> Where real consent cannot be obtained from adults with impairments in understanding or communication, wherever possible the investigator should consult a person well-placed to appreciate the participant's reaction, such as a member of the person's family, and must obtain the disinterested approval of the research from independent advisors (p. 5).

In order to facilitate the participants' understanding, the information sheet and the consent form (see Appendix A) are designed specifically for people with learning disabilities according to information sheets and consent forms that were used by Humlin (2003), Read (2004) and Karavella (2005). As Cable, Lumsdaine and Semple (2003) supported, in order for individuals to be properly informed, the researcher has to take into account the client's abilities and language.

If they chose to, participants can have a carer or a friend with them that would also give consent for the participant with learning disabilities to take part in the research. A separate carer consent form is developed for this purpose (see Appendix A). The notion of allowing participants to decide on their own, if they wished to, was based on the statement of the Department of Health: "It should never be assumed that people are not able to make their own decisions, simply because they have a learning disability" (2001, p. 1) and on the notion that as a general principle adults that are assumed to have capacity

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applies "just as much to an individual with learning disabilities as to any other adult" (Panting, 2002, p. 80). Participants should also be free from undue pressure to consent (Willner, 2003). Making sure that the participants understand their right to withdraw at any time is also a vital point to be aware of.

Additionally, due to the possibility of evoking feelings when revisiting an experience of change, participants will be provided with a list of services (see Appendix A) that they could contact, if they wished to further explore their feelings evoked from our discussion with a professional.

Semi-structured interviews

I am intending to use semi-structured interviews for this research. Selecting interviews as a method was based on relevant literature. Thomas and Woods (2003) stated that many individuals with learning disabilities are still able to have a coherent verbal conversation even if their learning disability affects to a small degree their ability to communicate. Smith, Harre, and Langenhove (1999) highlighted that with semi-structured interviews the participant can be regarded as the expert and is allowed the maximum opportunity to tell his/her story.

An Interview Schedule (see Appendix A) is developed taking into account previous research. Topics are arranged in an order so that the more sensitive or private topics to be addressed later in the interview after rapport has been established (Smith, Harre & Langenhove, 1999; Willig, 2001; Humlin, 2003).

Questions are developed for each topic. Both open ended and close-ended questions are used. An effort to minimize the use of 'yes' and 'no' questions has been made due to the tendency of people with learning disabilities to respond affirmatively (Sigelman, Budd, Spanhel & Schoenrock, 1981a; Sigelman, Budd, Spanhel & Schoenrock, 1981b; Sigelman et al., 1982). A series of prompts is also used in each of the questions if they were needed to elicit more information in the interview (Humlin, 2003). The language and the vocabulary of the questions will be adjusted to each participant's level of understanding. (Smith, Harre & Langenhove, 1999; Goodley, 2000).

Procedure

I estimate that interviews may last approximately 35-45 minutes each. However, the place in which the interviews will be conducted is still under consideration. Some options would be to visit people at their home, use a counselling room of an organization (maybe one in my current placements) or alternatively a mutually agreed place between myself and the participant. I am planning to record my data with the use of a tape recorder and to later transcribe each interview verbatim. According to Charmaz (1999), the researcher's involvement in data analysis "is explicitly aimed towards developing theory" (p. 34) and helps him to get closer to the content of the interviews and connect to the words used (Humlin, 2003). Finally, I intend give feedback to participants regarding the analysis during[14] and in the end of the research.

Analytic strategy: Grounded theory

I intend to use grounded theory as a method of analysis of my data. According to Glaser and Strauss (1967), grounded theory can be presented "either as a well-codified set of propositions or in a running theoretical discussion using conceptual categories and their properties" (p.31). In grounded theory one begins with an area of study and allows the theory to evolve from the data. This method of analysis also involves critical and creative thinking and implies being open, listening, "giving voice" to participants and representing their views as accurately as possible (Strauss & Corbin, 1998).

In addition, this strategy takes into account multiple viewpoints of an event in order to reach the participant's quality and intensity of experience taking into account their personal perspectives. Grounded theory uses interviews as a common source of gathering data and regards interviews as 'directed conversations' following an open-ended conversational style (Pidgeon & Henwood, 1996). A special strength of this approach is its ability to concentrate on the process rather than on the outcome (Murray & Chamberlain, 1999). I decided to use grounded theory analysis because this method would be systematic for studying subjecting experiences and "generating theory that was grounded in the data" (Millar, 2003, p.18).

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[14] In order to involve participants in member validation (Henwood & Pidgeon, 1992; Smith, 1996).

Provisional Timetable

My plan for the next months is to allocate time to each step of this doctorate. I expect that during April and July 2006 I will be advertising the study, recruiting participants and collecting data; This process will entail finding appropriate participants and conducting the interviews. Between August and September 2006, I am aiming to transcribe verbatim from the tapes and continue with the data analysis. From October 2006, I am planning to continue with writing up the doctorate. However, I expect to be reading and collecting more relevant literature throughout these months and to be working on the other components of the Dpsych as well.

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Appendix 6a: Information Sheet

<u>Information Sheet</u>

Margarita is trying to find out how people (people with learning disabilities) feel about themselves when they change home. This finding out work is called research.

Margarita wants to find out if moving home has made a difference to me. This means me answering some questions about how I feel and me telling my story about it.

I can choose to answer the questions or not.

If I think it's helpful to have a carer or a friend with me when Margarita talks to me about the finding out work, that's ok.

If I choose to answer the questions, Margarita will tape my discussion. Margarita will keep my tape safe until the finding out work has finished.

I can choose to have my answers recorded in a tape or not.

My story will be written down, so that other people can read it and learn from it. When my story is written down, my real name and address will not be used.

I can choose to have my story written down or not.

If later I change my mind, I can ask not to be part of the finding out work. I only have to tell Margarita.

AGREEMENT TO PARTICIPATE IN THE FINDING OUT WORK

Date:

Name:

<u>Please circle Yes or No</u>:

Margarita has explained to me what she will do in the finding out work.

Yes   No

She has shown me and read to me the information sheet

Yes   No

I have had the chance to ask questions and to think about the answers.

Yes   No

I know that I do want to be part of the finding out work and, if I change my mind, I can stop at any time.

Yes   No

I understand that the discussion for the finding out work will be tape recorded.

Yes   No

I understand Margarita will be writing down my story from the tape.

Yes   No

I am happy for my story to be written down without showing my name in the finding out work.

Yes   No

Signature (or mark) of the person in the finding out work

Signature of Margarita, the researcher

Signature of the parent or carer (if applicable)

Carers Information Form

Dear Sir/Madam,

You are invited to give your consent for (name of participant) to participate in a research study. Please take your time to read the following information and feel free to ask any questions before giving your consent.

My name is Margarita Karavella and I am conducting research on the impact of change of home on the identity of people with learning disabilities. This study is part of my Dpsych in Counselling Psychology at City University and it is supervised by Dr Deborah Rafalin.

The purpose of this study is to offer insight into the identity of people with learning disabilities when they change homes and to broaden our understanding of their experience.

By giving your consent, (name of participant) will be asked to sign a consent form after I read and explain to him/her thoroughly the information sheet and what will take place in the study. (Name of participant) will be provided with a copy of his consent and information sheet. I will also ask (name of participant) to fill in a demographics form asking some information about age, gender etc. In addition, I will invite (name of participant) to take part into a one-to-one interview with me regarding her experience of changing homes and how he/she sees him/her self now. This process will take approximately 40 minutes to an hour and the interview will be tape recorded. The tapes and forms will be kept safe throughout the process of the research.The interview will be in the form of a natural conversation and there will be no right or wrong answers. In the end of the interview, I will provide (Name of participant) with a list of services for people with learning disabilities if she wishes to use any of them in the future.

(Name of participant)'s participation will be voluntary. If at any point (name of participant) wishes to stop the interview or to withdraw from the research, (name of participant) is free to do so without any implications. (Name of participant) does not have to participate if he/she doesn't want to. If (name of participant) decides to withdraw from the study, his/her forms and tape will be immediately removed and destroyed.

(Name of participant)'s data and your consent will be kept strictly confidential and will be used only for this research study and its potential publication. The data will be presented in a way that all identifiable information will be removed from the participants.

(Name of participant)'s participation will assist us understand the experience of changing homes for people with learning disability and possible shifts in their identity. It will also help us explore ways of coping for this client group when changing home.

In the end of the study, the forms and tape will be destroyed. Upon completion of the research, I will send (Name of participant) a brief summary of the results if he/she wishes to.

If you have any questions about the study, please contact:

Margarita Karavella, City University, Department of Psychology (Dpsych in Counselling Psychology), School of Social Sciences, Northampton Square, london, EC1V 0HB
M.Karavella@city.ac.uk mobile: 07906419686

Dr Deborah Rafalin, City University, Department of Psychology, Counselling Psychology Programme, School of Social Sciences, Northampton Square, london, EC1V 0HB
d.rafalin@city.ac.uk telephone: 020 7040 0167

Carer Consent

I have read and understood the information about the research and all my questions have been answered by the researcher.

I give my consent for (Name of participant) to participate in this research study.

Please print your name below to show that you give your consent.

Name

Signature

Date

Thank you for taking part in this study

One of the two copies is yours to keep for reference.

If you found it difficult talking to Margarita and

If you want to talk more about changing home,

You may want to talk to the people you live with

But if you want to talk to someone you don't know about changing home,

You can contact someone from this list

If you do not know which number is best for you,

Please call Margarita

Or

You can ask your carer to help you

Services for people with learning difficulties

British Association For Counselling
They can help you find a person to talk to in your area

1 Regent Place
Rugby
Warwickshire
CV21 2PJ

Tel. 0870 443 5252
e-mail : bac@bac.co.uk
Web Site: www.bac.co.uk

British Association for Counselling and Psychotherapy (BACP)

They can help you find a a person to talk to in your area

BACP House
35-37 Albert Street
Rugby
Warwicks, CV21 2SG
Phone: 0870 443 5252
Fax: 0870 443 5161
Minicom: 0870 443 5162
email: bacp@bacp.co.uk
Web: www.bacp.co.uk

United Kingdom Council for Psychotherapy

They can help you find a a person to talk to in your area

2nd Floor
Edward House
2 Wakley Street
London EC1V 7LT
Phone: 020 7014 9955
Fax: 020 7014 9977
email: **info@psychotherapy.org.uk**
Web: **www.psychotherapy.org.uk**

Sanibel Counselling Service

Sanibel is a counselling service giving help to people with mental health problems in London. They can help you find a person to talk to.

64 Station Road,
Chingford,
London
E4 7BA
Ms Katie Crooks
Office Manager
Tel : 020 8506 3610

www.sanibel.org

Down's Syndrome Association

They give information and support to people with Down's Syndrome and their families and carers.

The Langdon Down Centre
2A Langdon Park
off Kingston Road
Teddington
TW11 9PS

Public Tel: 0845 230 0372
Fax: 0845 230 0373
E-Mail: info@downs-syndrome.org.uk
Website: www.downs-syndrome.org.uk

Elfrida Society

They can help you find a person to talk to. They can give you information for health, advocacy, groups and your rights.

34 Islington Park Street
London
N1 1PX

Public Tel: 020 7359 7443
Fax: 020 7704 1358
E-Mail: elfrida@elfrida.com
Website: www.elfrida.com

Respond

They can help you find a person to talk to and give you support, if someone has harmed you.

3rd Floor
24-32 Stephenson Way
London
NW1 2HD

Public Tel: 0808 808 0700 helpline
Admin Tel: 020 7383 0700
Fax: 020 7387 1222
Minicom: 0808 808 0700
E-Mail: helpline@respond.org.uk
Website: www.respond.org.uk

Foundation for People with Learning Disabilities

National charity that tries to make better your life through research and community services. They can help you find a person to talk to.

7th Floor
83 Victoria Street
London, SW1H 0HW

Phone: 020 7802 0301
Email: fpld@fpld.org.uk
Web: www.learningdisabilities.org.uk

British Institute for Learning Disabilities

A charity that tries to improve the quality of life of all people with a learning disability. They can give you information about many things and might help you find a person to talk to.

Campion House
Green Street
Kidderminster
Worcestershire, DY10 1JL

Phone: 01562 723010

Fax: 01562 723029

Email: enquiries@bild.org.uk

Web: www.bild.org.uk

Mencap

Mencap can give you and your carer support, advice and information. You can phone them or go and see them.

123 Golden Lane
London, EC1Y 0RT

Phone: 020 7454 0454

Fax: 020 7696 5540

Email: information@mencap.org.uk

Web: www.mencap.org.uk

Mencap: Learning Disability Helpline:

The Mencap Helpline gives information and advice. It can help you with problems with the care you get, money, housing and work. It is also happy to help your carer.

Mencap
123, Golden Lane
London, EC1Y ORT

Phone: 0808 808 1111

Fax: 020 7608 3254

Minicom: 0808 808 8181

Email: help@mencap.org.uk

Web: www.mencap.org.uk/helpline

People First

People First is an organisation run by and for people with learning difficulties to gain self advocacy skills. It can give you information, training and advice. They can help you find a person to talk to.

3rd Floor
299 Kentish Town Road
London, NW5 2TJ

Phone: 020 7485 6660

Email: general@peoplefirstltd.com

Web: www.peoplefirstltd.com

National Autistic Society

A charity that helps all people with autism and makes sure that they and their families get services for their needs.

393 City Road
London
EC1V 1NG
Tel: 0845 0704004

Appendix 8: Debriefing Form

Dear (Name),

Hello! My name is Margarita. I am a Psychologist.

I did a project about people with learning disabilities moving home.

We met together and you told me your story about moving home.

I also met with other 13 people with learning disabilities to find out their story.

In total I met with 14 people with learning disabilities.

I am now writing back to tell you what I found:
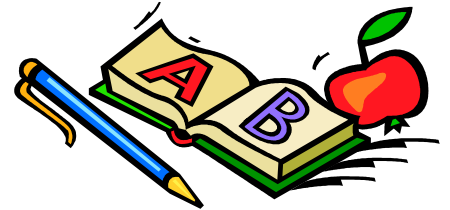
- People talked about their hobbies and what they liked doing

- Some people described what they looked like

- Many people said what their job was

- Some talked about their football team

- Some people explained why they moved

- Many said I had no choice

- Some said they felt happy
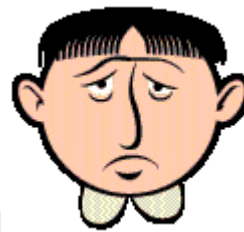
- Some said they were sad

- People said it was difficult to move to the new home

- People said that their family staff and friends played an important role in the new home

- People said things changed after moving

- People said that after moving home:
    o They were more independent
    o They need help with some things
    o They learned new things
    o They are doing things on their own

Appendix 9: Interview Schedule

Interview Schedule

Preliminary questions about identity
We are going to begin with some questions about identity. That means that I am going to ask you some questions about you, what you like, what you don't like etc.

Can you describe yourself?
What are your characteristics?
What do you do?
What are the things you are good at? What are the things you are not good at?
Some people like things about themselves, e.g. x, what do you like?
Some people do not like things about themselves, e.g. x, what do you not like?
How do you feel about yourself?
How would your best friend describe you? What would he/she say about you if I asked him/her?

A. **Background information about change of home**
Now I am going to ask you some more questions about moving home.

Before the change
Let's talk about what happened before you changed home.

Have you ever changed home? When was that?
Where did you live before the moving? What was your home like?
Who did you live with before? How was your relationship with….?
Have they told you before about moving home? Did you go to see your new place? Have they explained why you are moving? What did they say? If they did not say anything in advance, how did you feel?
Why did you move?

Moving
Now I am going to ask you some questions about the actual moving and how it was when you moved.

What happened?
What was the moving like?
Can you remember anything about it?
What did you do?
Who did you live with after?

B. Feelings immediately after moving home

First night
Now I'm going to ask you about your first night at your new home.

How did you feel when you moved?
How did you react? What did you do?
Did you have any thoughts about it? What did you think?

After moving: The first few weeks
Now I'm going to ask you what happened in the first few weeks that you were in your new home

What happened in your new home? How did you feel?
Did you have any feelings after moving? How long did you have these feelings for after changing home?

C. Change
Now, I'm going to ask you about changes after moving home

What has changed since moving? (environment, personality, money, friends) Was anything the same with your previous home?
What kind of changes happened in your life?
Was anything different? How? What was different?
Was it easy? Was it difficult?

D. Impact of changing home
Now, I'm going to ask you about how moving home has changed your life

Did changing home affect your relationship/interaction with other people? How? How do you see yourself after the change? Has your self changed?
Did it affect your college/school work?
How were you before and how were you after moving? How did you see yourself before? How do you see yourself now?
Was there any change in the way you feel about yourself? Can you give me an example?
Has (name) changed after moving?
How do you feel about you now that you changed home?
Has it changed how you feel about you or how others see you?

E. Change over time

How do you feel now about changing home?
Any memories?
Any thoughts?
How was this process for you? How has it changed overtime?

F. Things that helped and not helped
Now I am going to ask you about what was helpful or unhelpful

What helped?
Did you get any support?

Has someone helped you? How did they help?
What did not help?
Did you do something to feel better? What was that?
If a friend was changing home what would you say to them?

Ask: What name do you want me to use for you in the finding out work?

Appendix 10: Sample Transcript

Speaker key

IV	Interviewer
AM	Anne-Marie = Josephine

1. IV   Okay. Now I'm going to put this here…

2. AM   Yeah.

3. IV   …so I can hear you better. Okay. Now, what we're going to do now…

4. AM   Yeah.

5. IV   …is I'm going to ask you first some questions about yourself. Okay? I'm going to ask you some questions, um, about your identity.

6. AM   Yeah.

7. IV   I don't know if you know the word identity.

8. AM   Is it something to do with, um, you have to have a identity to go into college?

9. IV   Not so much. It has to do something about you. When we say identity we mean yourself.

[Handwritten margin note, top:] trying to understand identity / What identity means to her / identity is sth tangible → ID card. Perhaps / this is sth she has learnt.

[Handwritten margin note, bottom:] Her definition of identity / wrestling with according to 10,9 / Familiar of language in text?

1

10. AM Yeah.

11. IV Okay? Who is yourself?

12. AM My name is Anne-Marie ███

13. IV Mmh. Exactly. So, now I'm going to, to ask you to describe yourself.

14. AM British.

15. IV Anne-Marie. Ah, and, yes, you're right, you are British, ah, but what I have in mind is, for example, um, what are your characteristics? I mean, some people, to explain a bit more...

16. AM Yeah.

17. IV ...some people, ah, say that, oh, when they describe themselves say, oh, this is me, these are my characteristics, I'm good at this.

18. AM Oh, I'm good at, um, sculpture and things like that.

19. IV Okay. Okay. So, um, are there any things that you are, ah, not good at, for example.

20. AM Well, sometimes I'm not very good at doing... What can I say? What can I say? I'm not very good at doing money part, if you get what I mean.

21. IV Okay.

2

22. AM   I'm not very good at doing money.

23. IV   You're not very good at doing money.

24. AM   No.

25. IV   Okay. Okay. Um, if you were going to describe yourself, if I was saying, okay, Anne-Marie, describe yourself...

26. AM   Yeah.

27. IV   ...what would you say about yourself?

28. AM   Well, I think I'm nice and people say how helpful I am and things like that and how kind I am.

29. IV   Mmh. That's great. Fantastic. Okay. So, as I said before, ah, Anne-Marie, some people like things a lot about themselves.

30. AM   Yes.

31. IV   So, what do you like about yourself?

32. AM   Well, I like that I'm very nice to myself and things like that.

33. IV   Mmh-hh. Mmh-hh.

34. AM   I'm very nice to myself and I help myself and I do my own clothes and clean my own teeth.

Handwritten annotations (right margin):

things she's struggling with: money

sense of how others perceive her

she describes herself via how others see her

looking after?

nice helpful kind → caring persons

It seems that relationships are very important for her

taking care of herself / looking after herself

looking after herself → caring for herself

These is an element of independence here

Handwritten annotations (left margin):

difficulties with money

ID via others — caring, self celebrating via relationships, self

Liking oneself — appraise attitude towards self

Looking after oneself

Independence!

35. IV   That's great. That's great. Okay.

36. AM   I bath myself.

37. IV   You bath yourself. So, you do all these things yourself.

38. AM   Yeah.

39. IV   That's great. So, some people also don't like things about themselves. Is there anything that you don't like about yourself?

40. AM   Well, sometimes I can get het up a little bit, you know, and worry about things.

41. IV   Okay. So, this is the side of yourself that you don't like so much.

42. AM   Yeah.

43. IV   Okay. Brilliant. And, Anne-Marie, how do you feel about yourself?

44. AM   Well, I, sometimes I... Some days I feel as if I'm not well, if you get what I mean.

45. IV   Okay.

46. AM   And some days I'm Alright.

47. IV   Okay. Okay. So, so it depends on the day.

48. AM   Yeah.

4

49. IV   Great. Fantastic. So, if, if I would ask your best friend to describe

50. AM   Yeah.

51. IV   ...what would they say?

52. AM   They would say how nice I was and that I'm kind. Because I've got a girl, she's working in, Anne Petty her name is and she works in Platform One, is it, at Clapham Junction and, ah, she says how nice and kind I am.

53. IV   So, so people, they...

54. AM   And Felice, she's just gone off to St. Mary's.

55. IV   Mmh. So, all these people are saying how good and nice you are.

56. AM   Yeah.

57. IV   So, this is how you would, you would say that, that you are quite nice as a person and...

58. AM   Yeah.

59. IV   ...quite caring.

60. AM   Yeah.

61. IV   Is that, is that what they mean?

[handwritten margin note, left:] ID via others

[handwritten note, right:] It seems that she thinks of herself via how other people see her and what they say about her. Other people's opinion seems to be important to her.
Also she seems to exist via relationships.
She has an interesting memory of defeat with regards to outcomes & essays — is that something she was taught — does it enable + lead to remember?

5

62. AM   Yeah.

63. IV   And that you take care of people. Okay. So, this is great. You give me a lot of information about yourself. Now I'm going to ask you some information about changing home.

64. AM   Yeah.

65. IV   Okay? So… And specifically what happened before the change. I mean, you said to me that when you were around 17 or 20 you were living with your parents.

66. AM   Yes. Well, I got on Alright with mum and dad and we used to go to the Cambley Working Men's Club some nights and go and play bingo.

67. IV   Right.

68. AM   And it, I must have been about 21 when mum couldn't put up with me no more 'cos she had to bath me 'cos I was a backward child.

69. IV   A backward child?

70. AM   Yeah.

71. IV   What do you mean, a backward child?

72. AM   Well, they said I, I was lucky to be alive.

73. IV   Okay. Okay. So, so, um, before, before the change of home, were you living with your parents?

Handwritten annotations:

family relationship with parents / measures

identifies with family

lack of self-care?

reason for the move? ID label (LD) Stigma

feared view? others' view internalized?

relationships with parents — doing things with family

reason for moving from home house? inability of her mother to look after her; perhaps she perceives her LD as part of you ID "backward child" perhaps sth that she was taught

she was a burden to her mother

she had to be physically looked after

unbearable, difficult to be with, put up with

perhaps this is what others told her & a story about that she was told that she was told...

74. AM   Yes.

75. IV   Mmh. Mmh. So, what, what was your home like when you were living there?

76. AM   Oh, it was nice, a big, nice big house that had three bedrooms, a bathroom, a toilet downstairs, a toilet upstairs, an airing cupboard.

77. IV   Mmh-hh. Mmh-hh. So, you said you lived...? Who did you live with? Who did you live before? Only with your parents?

78. AM   I lived, um... Then with my, I met my husband, I moved into the flat at Tawley [?] Lane.

79. IV   Okay. So, this was when, this was after...

80. AM   Yeah.

81. IV   ...after your parents?

82. AM   Yeah.

83. IV   But who did you live with when you lived at your parents' house?

84. AM   Oh, there was my sister and my brother.

85. IV   Okay. So, how, how was your relationship with your parents and family?

86. AM   Alright.

Handwritten margin notes:

Memories of family home & the space

Life past the move / Life before the move

Life post the move: Living with Siblings / Family

memories of the space / description of space

family home / the family home / physical space

87. IV   Okay. Um, but do you remember anything particular?

88. AM   Well, my brother, when I was about seven years old, he threw me in the sea.

89. IV   He, he threw you in the sea? Mmh.

90. AM   And I then... He, he was only about... How old was he? He was about ten...

91. IV   Okay.

92. AM   ...and I don't think he realised that I couldn't swim. I couldn't believe that I could swim.

93. IV   Mmh. You, you couldn't believe that you could swim?

94. AM   Yeah.

95. IV   Great. So, you said before that you moved because your mum couldn't, couldn't put up with you.

96. AM   Yes.

97. IV   So, how, how was your relationship with your mum?

98. AM   It was alright. I got on well with her but she said that in the end I irritated her.

99. IV   You irritated her. And, and is this the reason that you moved?

Handwritten annotations (right margin):

fear?
→ wanted to get rid of her? jealousy?

theory of mind.
trying to justify him → advanced thinking
that she could swim?
surprised? of her strength.
she saves herself → shows resilience

It seems they had a comfortable relationship but it seems that in the end it deteriorated.
She is very insightful of how her mother's behaviour impacted on her — she is able to
was wary of mind —
recognize her mother's feelings.

Handwritten annotations (left margin):

Memories with brother.
why living with family?

imagine...
Formative / Not believing in her own capabilities, then?

Relationship with difficulties in her self and her impact on others

8

100. AM   Yes.

101. IV   Mmh. Mmh. Okay. How, how do you feel about that, that you moved because of this reason?

102. AM   Well, I felt... At first I didn't want to really come here but my, it was my brother that said I've got to come here.

103. IV   Right. Okay.

104. AM   But now I've got used to it, I'm alright.

105. IV   Mmh. Mmh. So, when you first moved, when you first moved, had they told, well, did they tell you that you're going to move?

106. AM   Yes, they told me I was going to move into here.

107. IV   Okay. So, before, before you came into here, did you see this place?

108. AM   Yes.

109. IV   Okay. Okay. Ah, and have they explained to you why you were moving here?

110. AM   They didn't explain to me, no.

111. IV   They didn't explain to you.

Handwritten margin notes (left):

Feelings about moving
Lack of choice
Dependence

Acceptance of settled home
Feelings about settled home
Lack of control/choice
Dependence ↓
Lack of collaboration?

Lack of explanation about the move
Dependence
Lack of control?

Handwritten margin notes (right):

Not wanting to move; suppose to move
Lack of choice, of control → dependence?

acceptance? → did she compromise due to getting use d to new environment? Or Feelings about current home → gave up → there's nothing she could do about it

imposed move
Lack of control → dependence
not collaborative

They gave her no explanation about the move → confusion?
↓
dependence
→ depends on their explanation
→ frustration?

Memory of another care home / Memory of previous home

another transition, move - previous home

112. AM No. Oh. and I... By the way, I was at St. Mary's down the road there for a while.

113. IV Ah, okay.

114. AM And I moved from there to here.

115. IV Okay. So, so you are saying that before you were in another care home and then you came here.

116. AM Mmh. Yes.

117. IV Okay. But, but, as you said before, is, is that they didn't tell you.

118. AM Yeah.

119. IV Okay. Okay. Um, so if, um... So, how did you feel when they didn't say anything to you, they didn't explain why you...?

Feelings (prior the move) was ... had no explanation Fear/Uncertainty

Uncertainty, anxiety, confusion

120. AM Well, I felt awful. I, I didn't know what was happening.

121. IV You didn't know what were, was happening.

122. AM No.

123. IV Mmh. Mmh. Okay. And, um, any more feelings that you had?

Adjustment linked to individuals

24. AM Well, I... When I when I moved from St. Mary's, I didn't know why they moved me first off until I got used to it and I got used to Barbara.

23. IV Ah...

Poor Adjustment to understanding

confusion, uncertainty. It seems that adjustment to new home and getting to know people helped her to rationalize about the reason of the move. did she use rationalization as a defence mechanism to combat her...

10

125. IV   Okay. So, again, when you moved here you were not quite sure about why they moved you…

126. AM   Yeah. Yeah.

127. IV   …or what was going on. Okay. Um, and how did that make you feel?

128. AM   It made me feel sad at first.

129. IV   Sad at first.

130. AM   Then I got used to it.

131. IV   Mmh. Were you confused at all?

132. AM   Yes.

133. IV   Mmh. Mmh. Yes. And that's… You know, sometimes that can happen.

134. AM   Yeah.

135. IV   So, when, when you first moved from your parents' house, who did you live with? I mean, I know you lived in, in St. Mary's.

136. AM   Yeah.

137. IV   But do you remember who did you live with at all?

Handwritten annotations (left margin):
Feelings about the move / Sadness
Acceptance (getting used to / new phenomena)
Acknowledging confusion

Handwritten annotations (right side):
Sadness

Acceptance?
Is this due to settling down? went up...
Is this an element of ... moving on?
Is this due to her lack of control → so
she couldn't do anything about it so
accepted it?
→ accepting confusion

Remembering fellow care home residents.

Sadness + loss leaving friends behind physicality

Remembrance
Memory about fellow residents (who fellow residents were)

Loss?
Feeling sad about leaving to

Loss/Sadness in physicality

138. AM   There was Cathy… What's her name? Cathy ██, ah, Lenny █, um, Deirdre █ Irene somebody but she's dead now.

139. IV   Okay. So, you lived with other, with other people.

140. AM   Yes.

141. IV   With other residents there.

142. AM   Yeah.

143. IV   Okay. So, what I'm, what I'm going to ask you next is some questions about what, the day that you moved…

144. AM   Yeah.

145. IV   …to the care home, okay, so, so that we can discuss what, what happened that day when you moved.

146. AM   Yeah.

147. IV   Okay. So, so what, what happened that day when you moved?

148. AM   Well, I felt sad because I was leaving all my friends there behind.

149. IV   Yes. And your mum in, when you were living with your parents.

150. AM   Yeah.

151. IV   Right. Right. Um, and do you remember what was the moving like when you moved all your stuff to the…?

12

Memory of the move
physicality of the move

Memory of the move
Physicality of the move – the move / practicalities

Loss/regret
Ownership
lack of control

memory of the move
physicality of the move
anxiety?

moving stuff = physicality

sadness?
loss? regret?
She could not take all her things with her things with her storage over have no storage – she has frozen – seems to have done this unwillingly.

uncertainty? not knowing where they are
ownership; she had her own things

152.	AM	Well, it was quite hectic.
153.	IV	Hectic?
154.	AM	Yeah.
155.	IV	Mmh. So, what happened in it was hectic?
156.	AM	Well, trying to move all my stuff together.
157.	IV	Mmh. Mmh. Mmh. So, it must have been quite, um…
158.	AM	Yeah.
159.	IV	Um, can you remember anything about it specifically, when you were moving your stuff and…?
160.	AM	Well, um, there were all my… When I moved from the flat, there was all my lovely glass, glassware and glass cabinet and things like that and, ah, chairs and tables and… I had to get rid of them or have them put in store.
161.	IV	Right.
162.	AM	And I think they're still in store now. I don't know.
163.	IV	Mmh. So, so you had to… You, you, you couldn't take all of the, all of your stuff with you.
164.	AM	No.

Feelings about leaving her belongings/loved objects. Loss. uncertainty.

Sadness Loss. she must have felt not complete.

uncertainty → not knowing confusion ⇓ lack of control?

165. IV   Right. Right. This must have been really difficult.

166. AM   It was.

167. IV   Yeah.

168. AM   Because I, I felt awful about it.

169. IV   Mmh. Yeah.

170. AM   And I think it, they're still in store now. I don't know whereabouts.

171. IV   Mmh. Mmh. Yes. I do understand. So, so thank you, thank you for this information. It's quite good that you tell me also about your feelings...

172. AM   Yeah.

173. IV   ...and how you felt. Now I'm, now I'm going to ask you about your first night in your, in your care, in the care home.

174. AM   What, in here?

175. IV   Well, in, in St. Mary's when you first moved in there, in the first care home...

176. AM   Yeah.

difficulties at first night in new home
difficulties adjusting

annoyance
irri+ation
feeling disturbed => penetrated

anguish?
being kept awake, agitated
lack of control => depending on the
staff
feeling stressed?

anger, frustration
irritation

negative feelings about new home
anger?
sadness?
dislike

---

177. IV   ...and your first night. I mean, how did you feel, when you
moved, in your first night?

178. AM   Well, there was a, a light that kept shining into my bedroom...

179. IV   Mmh-hh.

180. AM   ...and I didn't like it 'cos it used to keep me awake all night.

181. IV   Right. Right. Okay. So, what did you do when that light was
shining in your bedroom?

182. AM   I, I kept, I kept saying, getting out of bed and asking them in St
Mary's if I could, if they could sort of change my bedroom and they said no.

183. IV   Mmh. Mmh. And what did you do then?

184. AM   And I said, well, I said I can't sleep in here. I says that light keeps
irritating me.

185. IV   Mmh. Mmh. And, and how, how did you feel at that time, in your
first night?

186. AM   I felt really horrible.

187. IV   Mmh. Mmh. Mmh. And did you have any thoughts about it when
you...? What did you think when you first came?

188. AM   When I first come to St. Mary's, I thought, oh, it's horrible, I don't
like it here.

15

Difficulties adjusting at
new home

Difficulties adjusting
at new home
lack of control
/Dependence

Difficulties adjusting
at new home

Negative feelings at first
night at new home

Dislike about new
home/negative feelings
at first night at
new home

189. IV   Mmh-hh. So, now after moving, let's say… Let's go to some questions about after moving.

190. AM   Yeah.

191. IV   In your first week.

192. AM   Yeah.

193. IV   Okay? How, how was it the week afterwards? Was it, ah, ah, you know…? How was your new home in St. Mary's afterwards?

194. AM   It was alright then but that light still irritated me.

195. IV   Ah, that light still irritated you.

196. AM   Mmh.

197. IV   And how did you feel after a week? You, you mentioned in the first night you were quite, feeling not really well.

198. AM   Yeah. Yeah.

199. IV   But how were you feeling a week after?

200. AM   Ah, that light still irritated me but I got on alright with the other people.

201. IV   Mmh. Mmh. So, how, how, how long did you have these feelings after moving to your, um, to your care home?

Handwritten margin notes (left):

Feelings about new — acceptance? Difficulties at new home Acceptance? Adjusting at new home

Adjusting at new home — forming relationships at new home

Handwritten margin notes (right, top):

annoyance irritation again but with more acceptance that she kind of settled down stressewed Adjustment

Handwritten margin notes (right, bottom):

Adjustment? → forming relationships at new home irritation, annoyance it seems that there were things that still irritated her but that she had also started settling down.

Assertiveness / Independence?

she seems more assertive here, negotiating, expressing her wishes, and very much in control, communicating with staff she know what she's trying to get her needs met

202. AM Well, I said to. I think his name was… I'll think of it. Um… Oh, I can't think of s name now.

203. IV Okay.

204. AM Um, Finton [?], that's it.

205. IV Okay.

206. AM I said to Finton, I said, I don't like this light.

207. IV Mmh. Mmh.

208. AM And he said, well, well, would you like to move to 49 ▬… …

209. IV Right.

210. AM …and change room with Deirdre ▬▬? I said, I wouldn't mind.

211. IV So, that's why they, they moved you.

212. AM Yeah.

213. IV Oh, that's great. So, when…? After your first week, okay, ah, what was good about…? Was there anything good about moving home?

214. AM Well, I really enjoyed moving here.

215. IV Okay. In, in your second one.

positive emotion → positive experience seems pleased of current home she seems that she enjoys her stay enjoys her stay here

Positive feelings about moving to current home

216. AM   Yeah.

217. IV   Okay. But not in the first one.

218. AM   No.

219. IV   Okay. Was, was there anything, ah, that was helpful in St. Mary's when you first moved? Because you said that, you know, in the beginning it was quite horrible, then you got used to it.

220. AM   Yeah.

221. IV   I mean, was there anything helpful?

222. AM   Yeah, there was… I used to help with the cleaning and things like that, which I do here.

223. IV   Mmh. But, ah, did someone help you…

224. AM   Yeah.

225. IV   …as well?

226. AM   Yeah. But my auntie Vella was, used to come and see me when I was in St. Mary's.

227. IV   Right.

228. AM   And she comes from, she comes from 49 ▬▬▬▬

[Handwritten margin notes:]

helping with household chores and continuing to do that at current home after home to help and look after? → degree of independence? coping?

Maintaining contact with relatives. acknowledging aunt's help.] pre-existing relationships

Degree of Independence? Being able to look after home.

Contact with pre-existing relationships. telecoms?

229. IV   Mmh.

230. AM   Ah, not, ah, 73 ▮▮▮▮▮ I mean.

231. IV   Mmh. So, so basically what happened is that, that, because you have visitors like your aunt, it was more helpful to you.

232. AM   Yeah.

233. IV   That's great. That's good. Was there anything unhelpful?

234. AM   Not really.

235. IV   Okay. Okay. Um, um, some people, for example, would say that it's very helpful if, um, the staff helps them around.

236. AM   Oh, yeah, the staff helped me around first off.

237. IV   Mmh. Mmh. And some people, and some people also say that, um, you know, some of the residents...

238. AM   Yeah.

239. IV   ...became afterwards their friends and they help.

240. AM   Yeah.

241. IV   Was that the case with you as well?

242. AM   Yeah.

Handwritten margin notes:

It is remarkable how she remembers her whole exact address → perhaps this is a way that she had to learn this. It is vital info for her

did not acknowledge sth unhelpful (even though she had difficulties adjusting)

Acknowledging the immediate help from staff

Not acknowledging unhelpfulness

Acknowledging help from staff

243. IV   Mmh. Okay. So, that's great. So, you had help from the staff…

244. AM   Yeah.

245. IV   …you, you know, you had new friends. That's great. So, now I'm going to ask you about what have changed, what has changed since you moved. Okay? Um, do you remember, when you first, um, moved from your, from your parents' home…

246. AM   Yeah.

247. IV   …do you remember what has changed since you moved in your new home?

248. AM   Um, well, a lot of things have changed. So, like Ava ▉▉▉ sent me out to get me some, um, is it, ah, um… She sent me out to get some washing powder…

249. IV   Mmh.

250. AM   …last Saturday but we usually have our cooked breakfast before we go out anywhere on a Saturday.

251. IV   Mmh.

252. AM   And she told me to go out and get some, um, washing powder for the machine 'cos we had run out of it and I said no. She said, you are. I said, well, I haven't had my breakfast yet.

253. IV   But, um, this was, this was last week.

Handwritten margin annotations:

Acknowledging change → does she mean personal change or change in relationship with staff?

difficulties in relationships with staff?

assertiveness: she stands up for herself → she has control over herself
Independence? Choice? Control?
is she were independent

compared to where others first some decided for her

Change → ?

Assertiveness Has choice have control →

254. AM   Yeah.

255. IV   This was last week. Now, what I'm asking you is when you first moved in St. Mary's…

256. AM   Yeah.

257. IV   …okay, and, you know, you, you left from your family home…

258. AM   Yeah.

259. IV   …what did change? Did anything change?

260. AM   No.

261. IV   Like your friends or your family?

262. AM   Oh, um, we still see… Cathy don't come up so much as she used to.

263. IV   Your friend Cathy?

264. AM   Yeah.

265. IV   Okay. Um, I mean, um, did, ah, did your relationship with your parents change, for example?

266. AM   Yes, 'cos they live in an old, they live in an old people's home now.

267. IV   Okay.

Handwritten margin notes (right):

Paradox
Not acknowledging change. This is a paradox because right before she spoke about her own change.

change in frequency of visits from Cathy → growing apart.

Old people's home = grew old
Parents growing up = change
is she referring to her parents growing old? By them changing home/regime

Handwritten margin notes (left):

Not acknowledging change

Growing apart with friend
(is this change)

Parents growing up → change
home due to old age

21

268. AM   It's Flat A1, ▮▮▮.

269. IV   Mmh.

270. AM   Ah, ▮▮▮ ah, ▮▮▮ I'm not quite sure of the code number.

271. IV   That's okay. Um, but, um, ah, did anything else change? You said that your friends didn't come so often.

272. AM   Yeah.

273. IV   And your parents also changed home…

274. AM   Yeah.

275. IV   …during this period.

276. AM   Yeah.

277. IV   Um, was anything the same with your parents' house?

278. AM   Well, what I can gather, somebody's moved in there and into the ▮▮▮ Road where mum lived.

279. IV   Mmh.

280. AM   And they, um, they, ah…

281. IV   They moved in your old house.

Handwritten margin notes:

Contextual information
Friends new address

parents new address
Again it is remarkable how she remembers learned info.
Is it sth that she was taught to remember
ie. like children remembering their address and telephone number

Change in terms of home
old family home; changing owners over time

Someone else living in her family home now where her parents lived
Family home changing owners
what happened with regards to her family home
Time → things moving on
Loss?

282.	AM	Yeah.
283.	IV	Okay. So, so that's great. So, so these are quite a lot of…
284.	AM	Yeah.
285.	IV	…a lot of changes.
286.	AM	Yeah.
287.	IV	Like you said that your parents moved in, someone else moved in that house…
288.	AM	Yeah.
289.	IV	…ah, you, you know, your friends changed.
290.	AM	Yeah.
291.	IV	Um, did you find any similar things like when you were living with your parents here?
292.	AM	No.
293.	IV	Okay. So, was everything different?
294.	AM	Um, no, nothing seems different. It all seems the same to me.
295.	IV	It all seems the same. Was it easy when you moved home?

Seeing family ~~residence~~ and current home as similar – not acknowledging any differences

Paradox? She does not acknowledge differences between her family home and her ~~parent~~ current home

23

Acknowledging difficulty moving

finding the practicalities of the move difficult

Acknowledging difficulties in settling down at new home due to emotional state

Change of emotional state over time

Uncertainty

296. AM No, not really. [laughs]

297. IV Okay. What was difficult about it?

298. AM Well, moving all your furniture and things like that

299. IV Mmh. Mmh. Any other things that were difficult?

300. AM Um, no.

301. IV Like settling down, for example?

302. AM Oh, yes, settling down 'cos I used to worry a lot.

303. IV Mmh.

304. AM But now I don't worry.

305. IV Okay. Okay. What were you worried about?

306. AM I don't know. I don't know what it was.

307. IV Okay. Okay. Now, thank you very much for these type of questions.

308. AM Yeah.

309. IV Now I'm, I'm going to ask you some questions about how changing home has affected yourself. Okay?

310. AM Yeah.

acknowledging that moving was difficult

Finding practicalities (the physicality of the move) difficult

Difficulties in settling down anxiety, fear?

change → settled, calm over time

not remembering? forgetting lack of insight or has she erased it to be able to cope due to intense anxiety? uncertainty

24

311. IV So, did changing home affect your relationship with other people?

312. AM No.

313. IV Okay. Okay. So, for example, has it affected your relationship with your parents?

314. AM Well, I don't see them so much as I used to.

315. IV Okay.

316. AM And I would like to go down more often, if I can.

317. IV Yes. Okay. Um, has it changed your relationship with your friends?

318. AM Well, I miss Cathy coming up and Lenny don't come up here so much as he used to.

319. IV Right.

320. AM 'Cos Lenny used to live here.

321. IV Right.

322. AM And before aunt Petty come here...

323. IV Yeah.

Handwritten margin annotations:

acknowledging that changing home did not affect that relationships usually other she explains afterwards because their age changes, that their age changes.

change in frequency of meeting with parents does she miss them?

desire to see parents more often → dependency?

missing friend sadness – loss?

→ friend lived with her → the change of home brought them apart / missing relative? / sadness / loss? / recalling contact with aunt

Acknowledging no change in relationships

change in contact with parents

Desire for more parental contact

Loss? Missing friend

Past contact with relatives

324. AM   ...and she... Um, Lenny weren't at St. Mary's when aunt Petty come here.

325. IV   Ah, okay. So, so a lot of residents moved around as well.

326. AM   Yeah.

327. IV   Okay. And, um, how do you see yourself after moving home?

328. AM   I see myself alright.

329. IV   Mmh. Did you see anything change in yourself?

330. AM   Well, I did used to not like going to the dentist but now I've got used to it now...

331. IV   Okay.

332. AM   ...'cos I go to Bollingbrook.

333. IV   Okay. So, it changed that...

334. AM   Yeah.

335. IV   ...that before you found it difficult, now you find it...

336. AM   Yeah.

337. IV   ...ah, you find it easier.

338. AM   Yeah.

Handwritten margin notes (left):

Remembering: keeping track of experiences

Perception of self after the move

Personal change over time: Adjustment

Handwritten margin notes (right):

memory
keeping track of time - calling, being fine around aunt Petty's visit.

Perception of self after the move (comes oozes the feeling of being calm, settled).

Personal change over time = overcoming difficulties. Few feats, perhaps
↳ growing, developing = learning on?
accepting things, getting used to them
being braver
Adjustment

Adjustment at college

Acknowledging impact of the move to college attendance

Positive - Feelings about self

Current emotional state.

Relationship with staff. Liking staff

339. IV   Um, when you moved home, did that affect you, did that affect you going to college?

340. AM   Well, at first I didn't like going to college…

341. IV   Mmh.

342. AM   …but now I've got used to it. I go every day and…

343. IV   No, I mean, when you changed home and you had to go to college afterwards, did that, um, change? I mean, when you, when you changed home, did that change, did, did, was it difficult to go to college to go to college because of that?

344. AM   Yeah. Yeah. Yes.

345. IV   Okay. Um, has changing home, ah, changed how you feel about yourself now?

346. AM   Alright. I feel alright and I feel more happy about it.

347. IV   You feel more happy about it.

348. AM   Yeah.

349. IV   What do you feel more happy about?

350. AM   Well, I like Barbara and Tracey.

351. IV   So, you like the staff.

Adjusting to college → getting used to it → embracing it as part of her routine

Acknowledging that there was a difficulty going to college due to the move. Move affects her going to college

Feelings about self calmer, happy, settled.

liking staff.

352. AM Yes. And I get on with the staff but the only staff I can't get on with is Eva…

353. IV Okay.

354. AM …because she, she sent me out, as I told you, last…

355. IV Okay.

356. AM …Saturday to get, ah… I don't know whether Barbara told you.

357. IV No, no, no.

358. AM She sent me out to get washing powder…

359. IV Mmh. You did tell me that.

360. AM …and I got a bit panicky 'cos I didn't have my breakfast before I went out.

361. IV Mmh. Mmh. Mmh. Yes. And that's very interesting as well. And do you remember at all…? And to, I'll bring you back when you changed home and you went from your parents' home here.

362. AM Yeah.

363. IV Ah, do you remember how you were before that and do you remember how you were after that?

364. AM Not really. I can't remember that.

Handwritten margin annotations:

Relationship with staff: not getting on with staff

Insight feeling safe in Routine

Issues with memory

conflict with staff? relationship with staff

insight in terms of it seeun that she feel safe in her routine and if she is out of it she get anxious → she gets anxious with change (as she did with the move though

perception of self after move
very general statement

acknowledging difference in itself

acknowledging her independence change in her self

wanting to learn more area for improvement/development → she seems to need help with many as she had said also in the beginning of the interview degree of dependence that comes with her perception of independence

future plans? aspirations for work, dreaming ambition and goals she has ideas and plans for the future? working choice. → sign of independence growing up maturing

Perception of self after move

acknowledging difference in self after move

Perception of independence (change? where is independence?)

sign of independence? Acc onto develop/Mae to learn

sign of independence) Work aspiration

365. IV   Okay. How were you after you moved to St. Mary's?

366. AM   Alright.

367. IV   Mmh. Were you different? I mean...

368. AM   Yes.

369. IV   In what way were you different? For example, some people might say I'm more independent now.

370. AM   Yeah, I am more independent now.

371. IV   Mmh. Or some people might say, oh, I made more friends or I can do more things now. Um...

372. AM   Yeah, well, I can... It's the money that I'd like to know more about.

373. IV   The money.

374. AM   Yes.

375. IV   Ah, yes.

376. AM   And I would at some point, instead of going to college, I would like to go out to work sometime, say like on a Saturday or, or a Sunday or something.

377. IV   So, after you moved home you had all these questions in your mind...
378. AM   Yeah.
379. IV   ...of things that you wanted to do.
380. AM   Yeah.
381. IV   Okay. And, um, how, how, how do you feel about yourself now?
382. AM   I feel happy in myself.
383. IV   Mmh-hh. Um... So, have, have, have you... After that, Anne, have you, have you changed after moving?
384. AM   Well, some people say I have, some people say I haven't. So, I don't know.
385. IV   What do you say?
386. AM   I say I have changed.
387. IV   Mmh. How?
388. AM   Well, I'm more happier and things like that.
389. IV   Mmh. Ah, and you do you feel about yourself that you have changed home?
390. AM   I feel alright.

Handwritten margin notes:

Current feelings about self / feeling positive about self

Self as defined by others, confusion.

Acknowledging self change

Positive change in emotional state

Feelings about self / emotional state

satisfaction
Current feelings about self

self as defined by others, depending on others? external locus of control?

acknowledging self - change / emerging sense of self

change in terms of emotional state

feelings about self / current emotional state / she seems calm & settled

30

Future aspiration : being more
independent → she seen to move
grown

391. IV Okay. Okay. Now, thank you very much for that. Now I'm going to, I'm going to ask you some questions about change over time. Okay? So, do you have any memories from when you moved home?

392. AM Well, I had a friend called Lill [?] and Gillian, Gillian and Bob and I used to be very friendly with them.

393. IV Mmh. So, this is what you remember when, when you were back in with your parents?

394. AM Yeah.

395. IV Um, over the time that you have been to St. Mary's and you have been here, did you have any thoughts about changing home? I mean, did you have any thoughts about the moving and what happened?

396. AM Yeah. But I would like to move with someone in a flat.

397. IV Okay. So, this is what you are thinking now.

398. AM Yes.

399. IV Okay. So… And, and now, if, if you go back and you, and, and we remember how you were when you were first with your parents…

400. AM Yeah.

401. IV …and then you changed…

402. AM Yeah.

31

future aspiration:

Acknowledging change over time

Attitude/judgement towards the ward

Help from staff

acceptance? Feeling settled?

Acknowledging change over time

Acknowledging help from staff

403. IV   …how was this all processed for you? How was this whole procedure?

404. AM   It, it was alright.

405. IV   Mmh. Has it changed? Has it changed over time?

406. AM   Yes, it has changed.

407. IV   Okay. Okay. Fantastic. Now, I'm going to ask you to talk about things that have, has helped you and things that haven't helped you.

408. AM   Yeah.

409. IV   Okay? Ah, through the change.

410. AM   Yeah.

411. IV   Ah, has anything helped?

412. AM   Yes. Barbara's helped me a lot. As you know, you just met Barbara.

413. IV   Yes.

414. AM   And I don't know whether you met Tracey. Have you?

415. IV   Mmh. Um, perhaps. It's a… You mean the staff have, has helped you.

acknowledging help from staff

continuing? No other source of support.

Help from staff on practicalities

Differences between people

Help from staff

Dependence in terms of self-care

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416. AM   Yeah. Yes.

417. IV   Okay. So, did you get any other support, apart from the staff?

418. AM   Um, no.

419. IV   Okay. Um, and how did the staff help?

420. AM   They helped a lot, in lots of ways. When I first come here, they helped me settle in and things like that.

421. IV   Okay.

422. AM   And things like that

423. IV   Okay. Mmh-hh. Was there something that was unhelpful, that did not help at all?

424. AM   Well, some people help and some people don't.

425. IV   Okay.

426. AM   Janet... The one who comes in, come in just then, Janet, she helps me.

427. IV   Okay. Okay.

428. AM   But I... They... There's one thing that they don't like me doing. I always forget to take a flannel and a towel in the bathroom upstairs...

429. IV   Okay.

---

acknowledging help from staff

Not getting other source of help

Help from staff on practicalities helping her settling down.

Difference between individual disappointment?

help from staff

Dependence she forgets and she has to be reminded in terms of self-care

Forgetting in terms of self-care

430. AM ...when I have a bath...

431. IV Okay.

432. AM ...and I, I, ah, and my oil and that, I always forget to take it with me. [laughs]

433. IV Okay. So, they help you remember that.

434. AM [coughs]. Yes.

435. IV Okay. And how about yourself? I mean, I know sometimes people help us, ah, but sometimes people do things to feel better, like they go for walks...

436. AM Yeah.

437. IV ...or listen to music. I mean, did you do something like that?

438. AM I, I listen to music...

439. IV Okay.

440. AM ...and I watch my telly...

441. IV Okay.

442. AM ...and I've got a, a video upstairs but it's broke... Ah, not a video, um, a radio but it's broken.

Coping via hobbies

IO via hobbies?
Coping via hobbies?

443. IV Okay.

444. AM So, I can't, I can't...

445. IV You can't...

446. AM ...use my tape.

447. IV Okay. But, ah, but these are the things that you did when you moved...

448. AM Yeah.

449. IV ...to make you feel better.

450. AM Yeah.

451. IV Did you do that as well?

452. AM Yeah.

453. IV Okay. And, um, my last question to you would be, if a friend was changing home, what would you tell them?

454. AM Well, I would tell them not to go because, [laughs], it's a lot of het up, if you get what I mean. A lot of...

455. IV Yes.

456. AM A lot of, um...

Perception of moving as a hassle ": negative attitude of moving

perception of moving as a hassle → negative aspect of moving → brings up anxiety?

35

457. IV   Hassle?

458. AM   Yes.

459. IV   Mmh. Would you advise them anything else?

460. AM   I would advise them not to go…

461. IV   Mmh.

462. AM   …but if they wanted to go… It's not up to me, it's up to them, isn't it?

463. IV   Yes, that's true. So, so this is how, how you feel about it, that, that if, if you were going to move again, you wouldn't want that.

464. AM   No.

465. IV   Mmh. Um, and how did you feel about moving from your parents' home to come here?

466. AM   I felt awful at first.

467. IV   You felt…

468. AM   I felt very strange.

469. IV   Mmh. Very strange. And, and do you still feel that, that it's very strange, although now you have gotten used to it?

Handwritten margin notes:

insight
she understands ~~[crossed out]~~ choice, control.

not wanting to move

Feelings regarding the move
awkwardness

Insight

No desire of moving again.

Negative feelings regarding the move.

awkwardness

Difficulty to settle down completely acceptance but also awkwardness she has settled down but still feels awkward - then she forces herself to settle down?

Lack of understanding feeling not heard, unfairness? feeling judged @ unfairly? attacked?

suggesting pseudonym.

Difficulty in adjustment

Lack of understanding Feeling misunderstood

Difficulties with stuff as new home

470. AM   I've got used to it but it still seems strange now and again, if you get what I mean.

471. IV   Right. Right.

472. AM   And I, I... Sometimes they keep on at me for no reason at all.

473. IV   Right. Right. So, sometimes there is conflict also inside the house.

474. AM   Yeah.

475. IV   Yes. Okay. So, these are the, the things that I wanted to ask you. Now, before we finish, I want... Um, as I said to you before, everything is between us and I'm not going to show it to anyone else.

476. AM   No.

477. IV   So, I'm not going to, ah, I'm not going to use your real name or address.

478. AM   Yeah.

479. IV   So, I'm wondering what... Because I can't use your name and say, oh, Anne said that. What kind of name would you like me to use for you, like a pseudonym, um, a fake name?

480. AM   What, like Josephine or something like...

481. IV   Yeah, yeah, yeah.

Choosing a pseudonym

Feelings about the interview

Feelings about the interview

Suggesting a pseudonym — she seems to have initiative and to have no issue to suggest things

Attitude towards the interview — positive feelings towards the interview

Acknowledging it was alright for her

482. AM …Josephine or something like that?

483. IV Yes. What would you like? Josephine?

484. AM Yes.

485. IV Okay. Okay. Brilliant. And now before we finish I'm going to give you… Before we finish I'm just going to give you… I mean, I'm just going to give you this list.

486. AM Yeah.

487. IV Now, how did you find talking to me?

488. AM Alright.

489. IV Did, did you like talking about changing home?

490. AM Yeah.

491. IV Okay. Um, was it easy for you or was it difficult at one point?

492. AM No, it was alright.

493. IV Okay. Now, what I'm going to give you, this is a, is a leaflet, a small leaflet…

494. AM Yeah.

495.

IV …and it says, you know, it says services for people with learning difficulties.

496. AM   Yeah.

497. IV   I mean, sometimes when we talk about, about, you know, a lot of changes in our lives, we have a lot of feelings…

498. AM   Yeah.

499. IV   …sometimes with it and perhaps, if you want to talk to someone else about that…

500. AM   Yeah.

501. IV   …ah, you know, you, obviously you can talk to the staff.

502. AM   Yeah.

503. IV   You can talk to Barbara about it but I'm also giving you this, ah, leaflet that has a lot of, um, organisations…

504. AM   Yeah.

505. IV   …for people with learning difficulties.

506. AM   Yes.

507. IV   If, for example, you want to talk more about changing home, you can approach these and the staff can help you with that.

508. AM   Yeah.

509. IV   Okay?

510. AM   Thank you.

511. IV   So, this is for you. Alright?

512. AM   Thank you.

513. IV   And, ah, we have finished.

Appendix 11: Sample Table of Themes of a Single Participant

<u>**Themes participant 4 Josephine**</u>
Definition of identity
>   Is it something to do with, um, you have to have a identity to go into college?(4, 8)

Uncertainty with regards to identity
>   Is it something to do with, um, you have to have a identity to go into college?(4, 8)

Familiarity of language in context
>   Is it something to do with, um, you have to have a identity to go into college?(4, 8)

Name as part of self ID
>   My name is (Name].(4, 12)

Group membership: Nationality as part of self ID
>   British (4, 14)

Self-ID through hobbies-activities
>   Oh, I'm good at, um, sculpture and things like that. (4, 18)

Challenges-Things she finds difficult: Struggling with money
>   Well, sometimes I'm not very good at doing… What can I say? What can I say? I'm not very good at doing money part, if you get what I mean. (4, 20)

Difficulty with handling money
>   I'm not very good at doing money (4, 22)

ID via others (via relationships)
>   Well, I think I'm nice and people say how helpful I am and things like that and how kind I am (4, 28)

ID via appearance
Liking oneself/ attitude towards self
>   Well, I like that I'm very nice to myself and things like that.4,32

Looking after oneself – independence
>   I'm very nice to myself and I help myself and I do my own clothes and clean my own teeth.4,34

ID via self care – Looking after oneself independence
>   I bath myself.4,36

ID via emotional state – Self ID tendency to get anxious
>   Well, sometimes I can get het up a little bit, you know, and worry about things.4,40

Self pathologising – mood fluctuations – Context ID changes
>   Well, I, sometimes I… Some days I feel as if I'm not well, if you get what I mean. And some days I'm Alright. (4,44-4,46)

ID via others
>   They would say how nice I was and that I'm kind. Because I've got a girl, she's working in, Suzan her name is and she works in Platform One, is it, at (place) and, ah, she says how nice and kind I am.
>   And Angela, she's just gone off to St. Luca's. 4,52-4,54

Family relationships – Activities with family

Yes. Well, I got on Alright with mum and dad and we used to go to the (name) Working Men's Club some nights and go and play bingo. 4,66

Lack of self care – reason for the move

And it, I must have been about 21 when mum couldn't put up with me no more 'cos she had to bath me…(4, 68)

ID label sigma

'cos I was a backward child. 4,68

Learnt view – others view – internalized

Well, they said I, I was lucky to be alive. 4,72

Memories of family home – the space

Oh, it was nice, a big, nice big house that had three bedrooms, a bathroom, a toilet downstairs, a toilet upstairs, an airing cupboard.4,76

Life prior the move

I lived, um… Then with my, I met my husband, I moved into the flat at Tawley [?] Lane 4,78

Life prior the move – Living with siblings family

Oh, there was my sister and my brother.4,84

Memories with brother when living with family

Well, my brother, when I was about seven years old, he threw me in the sea. And I then… He, he was only about… How old was he? He was about ten…and I don't think he realised that I couldn't swim. I couldn't believe that I could swim. 4,88-4,90-4,92

Not believing in her own capabilities? – Resilience

…and I don't think he realised that I couldn't swim. I couldn't believe that I could swim 4,92

Relationship with mother difficulties – Insight of herself and her impact on others

It was alright. I got on well with her but she said that in the end I irritated her 4,98

Feelings about moving – lack of choice – Dependence

Well, I felt… At first I didn't want to really come here but my, it was my brother that said I've got to come here.4,102

Acceptance of current home – Feelings about current home

But now I've got used to it, I'm alright.4,104

Lack of control/choice – Dependence – Lack of collaboration

Yes, they told me I was going to move into here.4,106

I, I kept, I kept saying, getting out of bed and asking them in St. Mary's if I could, if they could sort of change my bedroom and they said no (4, 182)

Lack of explanation about the move – Dependence – Lack of control

They didn't explain to me, no.4,110

Memory of another previous move – memory of previous home

No. Oh, and I… By the way, I was at St. Luca's down the road there for a while.4,112-4,114

Feelings prior the move about no explanation – fear Uncertainty

Well, I felt awful. I, I didn't know what was happening.4,120

Adjustment linked to individuals – From adjustment to understanding

Well, I… When I, when I moved from St. Mary's, I didn't know why they moved me first off until I got used to it and I got used to Mary.4,124

Feelings about the move – Sadness
It made me feel sad at first.4,128

Acceptance – Getting used of new home
Then I got used to it.4,130

Acknowledging confusion
Yes.4,132

Rememberance – memory about fellow residents – who fellow residents where
There was Katie… What's her name? Katie, ah, Lilly E, um, Dora, Irene somebody but she's dead now.4,138

Loss/sadness linked to physicality
Well, I felt sad because I was leaving all my friends there behind (4, 148)

Physicality of the move-memory of the move
Well, it was quite hectic (4, 152)
Well, trying to move all my stuff together (4, 156)

Loss/ regret
When I moved from the flat, there was all my lovely glass, glassware and glass cabinet and things like that and, ah, chairs and tables and… I had to get rid of them or have them put in store (4, 160)

Ownership
When I moved from the flat, there was all my lovely glass, glassware and glass cabinet and things like that and, ah, chairs and tables and…(4, 160)

Lack of control
I had to get rid of them or have them put in store and I think they're still in store now. I don't know (4, 160-162)

Feelings about leaving her belongings
Because I, I felt awful about it (4, 168)

Uncertainty
And I think it, they're still in store now. I don't know whereabouts (4, 170)

Difficulties adjusting at new home
Well, there was a, a light that kept shining into my bedroom…and I didn't like it 'cos it used to keep me awake all night (4, 178-180)
I, I kept, I kept saying, getting out of bed and asking them in St. Luca's if I could, if they could sort of change my bedroom and they said no (4, 182)
And I said, well, I said I can't sleep in here. I says that light keeps irritating me (4, 184)

Negative feelings at first night at new home/dislike about new home
I felt really horrible (4, 186)
When I first come to St. Luca's, I thought, oh, it's horrible, I don't like it here (4, 188)

Feelings about new home-difficulties at new home-adjusting at new home
It was alright then but that light still irritated me (4, 194)

Adjusting at new home-forming relationships at new home
Ah, that light still irritated me but I got on alright with the other people (4, 200)

Assertiveness/independence

Well, I said to, I think his name was… I'll think of it. Um… Oh, I can't think of s name now. Um, Finton [?], that's it.I said to Nick, I said, I don't like this light.And he said, well, would you like to move to 4 Brown Road…and change room with Irene? I said, I wouldn't mind (4, 202-210)

Positive feelings about moving to current home
Well, I really enjoyed moving here (4, 214)

Degree of independence: being able to look after home
Yeah, there was… I used to help with the cleaning and things like that, which I do here. (4, 222)

Contact with relatives
Yeah. But my auntie Vella was, used to come and see me when I was in St. Mary's. And she comes from, she comes from 4 Brown Road(4, 226-228)

Not acknowledging unhelpfulness
IV   That's great. That's good. Was there anything unhelpful?
AM   Not really. (4, 233-234)

Acknowledging help from staff
Oh, yeah, the staff helped me around first off (4, 236)

Change: assertiveness, more choice, more control
Um, well, a lot of things have changed. So, like Sheila [?] sent me out to get me some, um, is it, ah, um… She sent me out to get some washing powder…last Saturday but we usually have our cooked breakfast before we go out anywhere on a Saturday.And she told me to go out and get some, um, washing powder for the machine 'cos we had run out of it and I said no. She said, you are. I said, well, I haven't had my breakfast yet (4, 248-252)

Not acknowledging change
IV Did anything change?
AM No (4, 260-261)

Change in relationships: growing apart with friends
Oh, um, we still see… Suzan don't come up so much as she used to (4, 262)

Change in relationships: parents physically growing up
Yes, 'cos they live in an old, they live in an old people's home now (4, 266)

Contextual information
It's Flat A1, day Court. Ah, day Court, day Road, ah. I'm not quite sure of the code number (4, 268-270)

Change in terms of previous home
Well, what I can gather, somebody's moved in there and into the Free Orchard Road where mum lived (4, 278)

No change: Seeing family home and care home as similar
Um, no, nothing seems different. It all seems the same to me (4, 294)

Acknowledging difficulty in moving
No, not really. [laughs] (4, 296)

Finding the practicalities of the move difficult
Well, moving all your furniture and things like that. (4, 298)

Acknowledging settling down as difficult
Oh, yes, settling down 'cos I used to worry a lot (4, 302)

Change of emotional state over time

But now I don't worry (4, 304)

Uncertainty

I don't know. I don't know what it was (4, 306)

Acknowledging no change in relationships

IV   So, did changing home affect your relationship with other people?

AM   No (4, 311-312)

Change: contact with parents

Well, I don't see them so much as I used to (4, 314)

Desire for more parental contact

And I would like to go down more often, if I can (4, 316)

Loss: missing friends

Well, I miss Suzan coming up and Irene don't come up here so much as he used to (4, 318)

Past contact with relatives

'Cos Irene used to live here.And before aunt Helen come here…(4, 320-322)

Remembering: keeping track of events

…and she… Um, Irene weren't at St. Luca's when aunt Helen come here (4, 324)

Perception of self after the move

I see myself alright (4, 328)

Personal change over time: adjustment

Well, I did used to not like going to the dentist but now I've got used to it now…'cos I go to (area) (4, 330-332)

Adjustment at college

Well, at first I didn't like going to college…but now I've got used to it. I go every day and…(4, 340-342)

Acknowledging impact of the move to college attendance

IV I mean, when you, when you changed home, did that change, did, did, was it difficult to go to college to go to college because of that?

AM   Yeah. Yeah. Yes (4, 343-344)

Attitude towards self: Positive feelings about self

Alright. I feel alright and I feel more happy about it (4, 346)

Relationship with staff: liking staff

Well, I like Barbara and Tracey (4, 350)

Relationship with staff: not getting on

Yes. And I get on with the staff but the only staff I can't get on with is Eva…because she, she sent me out, as I told you, last…Saturday to get, ah… I don't know whether Sarah told you. She sent me out to get washing powder…(4, 352-358)

Insight

…and I got a bit panicky 'cos I didn't have my breakfast before I went out (4, 360)

…but if they wanted to go… It's not up to me, it's up to them, isn't it? (4, 462)

Memory issues

Not really. I can't remember that (4, 364)

Perception of self after the move

Alright (4, 366)

Acknowledging difference in self after the move
>IV Were you different? I mean…
>AM   Yes (4, 367-368)
Change? Perception of independence
>Yeah, I am more independent now (4, 370)
Areas to develop-more to learn
>Yeah, well, I can… It's the money that I'd like to know more about (4, 372)
Work aspirations
>And I would at some point, instead of going to college, I would like to go out to work sometime, say like on a Saturday or, or a Sunday or something (4, 376)
Attitude-current feelings-toward self
>I feel happy in myself (4, 382)
Self as defined by others-confusion
>Well, some people say I have (changed), some people say I haven't. So, I don't know (4, 384)
Acknowledging self change
>I say I have changed (4, 386)
Positive change in emotional state
>Well, I'm more happier and things like that (4, 388)
Attitude towards self
>I feel alright (4, 390)
Friendships prior the move
>Well, I had a friend called Luke and Nick and John and I used to be very friendly with them (4, 392)
Future aspirations: independent living
>Yeah. But I would like to move with someone in a flat (4, 396)
Current attitude towards the move
>It was alright (4, 404)
Acknowledging change over time
>Yes, it has changed (4, 406)
Help from staff
>Yes. Barbara's helped me a lot. As you know, you just met Barbara. And I don't know whether you met Tracey. Have you? (4, 412-414)
Acknowledging help from staff
>Yeah. Yes.(4, 416)
Confirming no other sources of support
>IV   Okay. So, did you get any other support, apart from the staff?
>AM   Um, no (4, 417-418)
Help from staff on practicalities
>They helped a lot, in lots of ways. When I first come here, they helped me settle in and things like that. And things like that (4, 420-422)
Differences between people
>Well, some people help and some people don't (4, 424)
Help from staff
>Janet… The one who comes in, come in just then, Janet, she helps me (4, 426)
Dependence in terms of self-care

But I… They… There's one thing that they don't like me doing. I always forget to take a flannel and a towel in the bathroom upstairs…when I have a bath (4, 428-430)

Coping via hobbies

I, I listen to music…and I watch my telly…and I've got a, a video upstairs but it's broke… Ah, not a video, um, a radio but it's broken (4, 438-442)

Perception of moving as a hassle: negative attitude of moving

Well, I would tell them not to go because, [laughs], it's a lot of het up, if you get what I mean. A lot of…(4, 454)

No desire of moving again

IV Yes, that's true. So, so this is how, how you feel about it, that, that if, if you were going to move again, you wouldn't want that.

AM   No (4, 463-464)

Negative feelings regarding the move

I felt awful at first (4, 466)

Awkwardness

I felt very strange (4, 468)

Difficulty in adjustment

I've got used to it but it still seems strange now and again, if you get what I mean (4, 470)

Difficulties with staff at new home: lack of understanding her

And I, I… Sometimes they keep on at me for no reason at all (4, 472)

Appendix 12: Master Table of Themes

Table of themes

Who I am

How I see myself

Where I come from

        I was born in Bristol (2, 88)

        'cos I was a backward child. 4,68

Things I am good at…things I enjoy doing

        I'm, I'm good with children (1, 14)

        I do needlework (2,6)

        I like music. I do love music (2, 428)

        Listen to music (3, 264)

        I watch me television and this timer.(10, 12)

        Um, I play football. I play pool and snooker (12, 18)

        Um I travel a lot; I travel a lot by train (3, 6)

        Oh, I'm good at, um, sculpture and things like that. (4, 18)

        I smoke and I drink tea (7, 226)

How I feel inside

        Well, sometimes I can get het up a little bit, you know, and worry about things.4,40

        I feel quite, quite good about myself. (1, 36)

        Well, I'm all right. [laughs (2, 350)

        All right (3, 31)

        I feel happy in myself (4, 382)

How others see me

What I look like

        white hair, brown eyes, wear glasses (12, 4)

        Ah, tall, dashing. Ah, lovely blue eyes, dark blond hair (8, 10)

How I come across

        Quiet (3, 36)

        Um, very committed person. Very honest. Very open. Always speaks the truth.

        Ah, very reliable. Um, very considerable, respectful. Um, strong (8, 12)

What is my role

        I'm their daughter (2, 142)

        I'm his niece (2, 148)

        Don't forget, I'm the eldest… I mean, I'm his sister's daughter as well (2, 150)

Groups I belong to

        I have learning disabilities (2, 182)

        Single(3,6)

        British (4, 14)

        Yeah, like we have got to take it in turns at night to cook the dinner. We're now allowed to be all in the kitchen at the same time. We've got different times for cooking (5.122)

        support the best football team and that is Arsenal (6, 72)

What I do for others

        Caring.(1, 22)

Well, I think I'm nice and people say how helpful I am and things like that and how kind I am (4, 28)

I used to help my father in the clinic because my father's a doctor. I used to be a receptionist, help him and do him drinks and see the patients and my, this, 'cos my father's a doctor.(2, 182)

The move

Why I moved

My mum couldn't cope with me 'cos she had a lot on her head then and my father, unfortunately he's a sick man now, he's 77, my dad, and my mum can't look after me and my father at the same time, you know (2, 158)

They said we've got to move out, because there's um, another bloke that has got cars and bikes, has got bicycles on it, so dad brought us out to Wales (11,80)

They had to close it down unfortunately (3, 55)

I had no control…I had no choice

Ah, I, I think somebody did, did let me know that I was going to move (1, 86)

Yes, they told me I was going to move into here.4,106

And then I was chucked into that place (8, 112)

And the service, of course, put me there, you know. I mean, the service user went and put me there (3, 130)

I was moved here (13, 70)

mind you, it wasn't my choice to be there, you know, so there wasn't a lot I could do, so… [sighs] (9, 114)

I didn't have… I didn't make the decision. The person from Barnett People Choice did it for me (6, 160)

I found it difficult

Yeah, of course, I found it difficult (2, 492)

Difficult (13, 190)

I felt good about moving

It's all right (3, 216)

Well, I really enjoyed moving here (4, 214)

I was relieved to get out of [unclear], relieved to get out, you know (6.346)

I was afraid

Well, I felt awful. I, I didn't know what was happening.4,120

Bit scared of moving out (5.202)

I think it's when I'm in a new place, like when I moved house, that was scary, because it was a new situation. (14, 38)

I was stressed

I found it really stressful (2, 138)

At first I thought, ah, okay, is she all right? I was a bit worried for my mum, I was concerned 'cos she's my mum, and I was very scared. I wasn't scared of the move; I was scared, well, my mum had moved [?]. I was worried about her, and it brought a lot of stress to me. So I was very stressed out, and very concerned with my mum. [Coughs] (8, 44)

I felt I lost something

The day that I moved out of that house, I just stood in the living room and I just cried. I just thought, well, what have I done, you know (14, 70)

When I moved from the flat, there was all my lovely glass, glassware and glass cabinet and things like that and, ah, chairs and tables and… I had to get rid of them or have them put in store (4, 160)

It wasn't very nice. I missed it very much (3, 91)

I felt sad

> (pause) a bit sad really (3, 71)
>
> Well, I felt sad because I was leaving all my friends there behind (4, 148)

My new home

How I felt about my new home

> ### I felt good
>
> > It was, it was very good (1, 124)
> >
> > Not really. It was all right. Very nice room.(3, 153)
> >
> > It was alright (4, 404)
> >
> > Oh, I did like it. (1, 60)
> >
> > I just felt… I felt really complete and I felt really happy, yeah. (6, 268)
> >
> > [Coughs]. When I first moved in, it was, ah, it was very good. I felt very nice. It felt, it felt like home, almost (8, 118)
> >
> > Exciting. I thought, this is my own house, I can put my own mark on it (14, 106)
>
> ### I did not feel nice
>
> > I was upset. I want to go home. [Unclear] I want to go back to Haven. Because I don't want to go [unclear]. [Unclear] the rest of them. [Unclear] (13, 76)
> >
> > It made me feel sad at first.4,128
> >
> > I felt very strange (4, 468)
> >
> > > #### I didn't like it
> >
> > But I didn't like it there but they used to take me on holidays with them (2, 132)
> >
> > When I first come to St. Mary's, I thought, oh, it's horrible, I don't like it here (4, 188)

I struggled settling down

> > *Well, there was a, a light that kept shining into my bedroom…and I didn't like it 'cos it used to keep me awake all night I, I kept, I kept saying, getting out of bed and asking them in St. Mary's if I could, if they could sort of change my bedroom and they said no And I said, well, I said I can't sleep in here. I says that light keeps irritating me (4, 178-184)*
> >
> > *Ah… I think the first two weeks were a little bit strange but after that I think I got… I started getting into it, you know, its… try to become a little bit more like home (9, 112)*

> ### I had to just get on with it
>
> > *But now I've got used to it, I'm alright.4,104*
> >
> > *No at first. But now I've got used to it (12, 167)*

Well, I... When I, when I moved from St. Mary's, I didn't know why they moved me first off until I got used to it and I got used to Barbara.4,124
Well, ah, how to get on with people (1, 164)
Well, at first I didn't like going to college...but now I've got used to it. I go every day and...(4, 340-342)

   Being with Other people affected me

      <u>My housemates affected me</u>

Because, ah, people were... Rian used to irritate a lot. He gets a bad mood with me and I don't like this mood... With me, I can't, I don't like this mood because he used to be tantrum on me (2, 126) You understand what I mean? He used to get bad moods and he's flying, of course, and, and I didn't like that house from the start (2, 128)
It was (difficult). Being with new people (6, 364)
It was very hard to get to know the people, and to know them individually. It took quite a while to get to know them (8, 94)

      <u>People outside affected me</u>

I think the first week or so it was... I was... I was still keeping in touch with my mum so... and I didn't particularly move all that far. I think that helped a lot(9, 116)
Well, people say to me, you're always welcome to come. They really are.(6,462)
And I talk to staff company [?] Not crying. I don't cry. I want you to know [?] 'Cos I talk to staff (13, 316)

Things changed after I moved

I've changed

   Yeah, I am more independent now (4, 370)

   Well, I mean, I've, I, I, I've grown up while I've been here (1, 242)Mentally (1, 246)

   I do more things (5.216)

   In ways, yeah, I'd say my personality changed. I'm kind of more relaxed; I'm kind of less stressed [?] [unclear]. No more worries, really (8, 186)

   I don't worry (4, 304

   I have become more happy (1, 224)

   I get happy. [laughs] (2, 336)

My relationships with others changed

   Oh, um, we still see… Cathy don't come up so much as she used to (4, 262)

   Well, this is… I want to say I don't see my mum so often. It's the best time. I see her usually, Margarita, at the weekend and I, I'm going tomorrow. I'm going to see her tomorrow (2, 332)

   (I see them) More often, more often (3, 196)

   It's better now. (3, 218)

My surroundings changed

   Not really. Smaller. (3, 155)

   The shops are around here (3, 182)

   Yes, a longer route.(3, 127)

Some things stayed the same

Um, no, nothing seems different. It all seems the same to me (4, 294)

I don't, can't seem to find any changes (1, 240)

As before (3, 160)

My self after the move

I need help with things

But I can't cook on my own. I'm not good in cooking, you know.(2, 262)

Well, they helped me to tell me how long to cook the food for as well. (5.110)

Yes, shopping, food shopping. (3, 140)

Sometime I… I do stuff on my own but by help (2, 256)

I am doing things on my own

Doing things on my own (1, 172)

Well, we've got… well, I've got more, uh, freedom here as well (5.192)

So I'm going through the process, sort of doing that now. So a lot of, a lot of things has happened since that… you know, recently. I moved into my new place now. I try and sort out bills. You know, like… So far, I've got electric run in…(8, 152)

I do everything for myself (6, 286)

I am learning new things

Yeah. Martin showed me how to do like breakfast and… (2, 262)

I learned a lot from moving about, from Crescent Road to where I am now. So at Crescent Road seems, we were covered in a lot of gas [?] and it dripped and stuff like that [?]. I didn't know anything about that, you see. And I did [unclear] for that [unclear]. You know, and things like that, really. I learned… (8, 166)

How I am feeling now

<u>I have mixed feelings</u>

I like the place. (3, 119)

Um, it's a bit strange really(3, 99)

I'm happy here because I like to sit in the house, do my washing, do my hoovering, do my bit of cleaning and, [laughs], you know… [laughs] (2, 252)

I get tied a lot here (2, 138) And I get frustrated with the house, as you know (2, 144)

<u>I miss…</u>

Yeah, I miss my nieces as well as… It's, it's not that I'm living in England and then she lives in America and it's really, really… It's not that… I miss them. (2, 48)

and I miss my mum as well, you know.I does miss… Um, I miss her a lot all the time, you know (2, 76-78)

Yeah. But there's one gap that's really empty. (6.504)My Suzy. (6.506)

<u>I feel lonely</u>

I don't have friends there. I'm, I'm like lonely all the time (2, 76)

Well, it's tough [unclear] I decided. Sometimes you can get lonely, and you can think about it. It can get lonely to think about it, can't you?(11, 154)

Well, when I'm at home I feel lonely. Even though I've got Betty with me, I feel lonely (6.60)

<u>I feel anxious</u>

But she gets tired, you know. She's not young like, you know.(2, 90)

Yeah, of course, I worry about my mother, you know (2, 166)

Yeah, yeah, it's, it's very stressful. It is [rattle] like that, because I… We'd just [?] had a carpet made (8, 158)

How I have made sense of it all

Um… Well, yeah, I mean, I [unclear] try to find… get everything right, at the time but you tend to learn as you go along.(9, 222)

I think it's when I'm in a new place, like when I moved house, that was scary, because it was a new situation. I knew I would have to move from my three bedroom to a two bedroom house. And I wasn't using the upstairs, because we were sort of renting the upstairs, and I wasn't usually upstairs in my old house. So I thought, well, it's not really [unclear] before I made that decision. But looking back on it now, I think it was the best decision that I've made (14, 38)

I have moved on

Well, it was mixed emotions, you know. Wondering if I'd done the right thing, but knowing, I thought that at the end of the day, it would be the right decision for me. I mean, other people might think it different, but for me, I mean, yes, I was sad that I was leaving, but I just felt that that part of my life had closed, that door was shut, and another door had opened. Because there's that fine line and it's sort of, it's like a misty line. You're going through this mist everywhere, going through the mist and coming out the other end(14, 76-78)

Um… Well, I think I got, ah… I think you always, like, remember… try and remember the good things. Ah… try and remember what sort of, ah, kind of things you like at a place. Ah… some of the things you don't like, I mean, if I was to move again, I would, like, maybe try… try and look around for a bit of, like, beauty. Ah… there's other things… well, that's… that's a good bit, you know, ah… where I would like to move into, um… I mean, at the moment, the place I'm in now hasn't got a garden. Where I was… where I was before, I was in… it was in the countryside, so… maybe, if I do move again, it's to a bit more… well, I'd like to have a garden because I want… because when I was living where I was before, I always used to live in town, bit more to, ah… more busses, more… a bit more…(9, 186)

What I would advise about moving home

I'd say, make sure you have loads of boxes. And lots of black [?] bags, and I always… (8, 284-286)

You know, if you're moving into that lot, like a location, do your research first. You know, do research on like… You know, do your research about moving. Like rent places, Councils, you know, buying or whatever. You know what I mean? Or rent houses, or whatever. Do your research first about before you move (8, 286)

And then when you've decided what you want [coughs], make sure you've got enough money to actually… to do it. Make sure you've got enough money to pay your bills like your gas, electric, your water. Your Council [unclear] tax… you know what I mean? And your rent. So make sure you've got enough money for that. Also, you've got to make sure you've got enough money if you're paying off and stuff like that. If there's already furniture, that's a big plus, I mean a big plus. But then you've got… And then you got to make sure you got money for people to move your stuff, and you get mad [?] with that. So you got to do a lot, a lot, a lot of research, a lot, a lot, a lot of… yeah, a lot of, like, just [coughs] do one step at a time. Don't just like, I

would say, oh, I'm going to move, 'cos it'll be a nightmare. Because you've got to do it. You've got to prepare for it [rattle] first (8, 288)

And research it. And then get rid of it. Yeah, write all it down (8, 290)

Um… um… well, I don't know, I would tell them to… take your time, consider what you need to do, you need to… you need to say, you know what I mean… make sure you've got everything sorted out before you actually move. I mean, ah… [sighs](9, 228).You know, it's… It depends how organised they are at the time, you know?(9, 230)

Appendix 13: Conceptual Model/Graphic Representation of the Findings

Who I am
How I see myself
How others see me

Myself After The Move
I need help with things
I am doing things on my own
I am learning new things
How I am feeling now
How I have made sense of it all
What I would advise about moving home

The Move
Why I moved
I had no choice
How I found moving
How I felt about moving

Things Changed After The Move
I've changed
My relationships with others changed
My surroundings changed
Nothing changed for me

The New Home
How I felt about my new home
I struggled settling down
Being with other people affected